Disability in under-resourced areas in the Western Cape, South Africa: A descriptive analytical study

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Declaration

I, Soraya Maart, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor part of it has been, is being, or is to be submitted for another degree in University of Cape Town or any other university.

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Acknowledgements

The research is conceptualised in the universal concept of UBUNTU. This traditional African term embodies a cardinal worldview of a human community. It also acknowledges both the right and the responsibilities of every citizen in promoting individual and societal well-being[1] [2]

I write these acknowledgements in recognition of those who have supported me on this journey:

UBUNTU - "I am because of you ……''

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UBUNTU can also be translated as human kindness…..

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[1] Kevin ChaplinThe Ubuntu spirit in African communities-

[2] South African Government Gazette, 02/02/1996.

UBUNTU is to strive to help people in the spirit of service…..

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UBUNTU means to value the good of the community above self-interest……

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UBUNTU does not mean that you should not enrich yourself, but envisage enriching yourself in a way that also enriches others….

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Umntu ngumntu ngabanye abantu

"People are people through other people"

Abstract

Title: Disability in under-resourced areas in the Western Cape, South Africa: A descriptive analytical study

Disability is a complex construct, and our understanding of it has evolved over the years from a purely medical description to encapsulating the experience of those with disability in the context in which they live. The International Classification of Functioning, Disability and Health (ICF) provides a framework to explore the concept in a biopsychosocial framework taking into account the interaction of a person with a health condition with their environment. The central purpose of this thesis was to explore disability within an under resourced context in order to provide data to service planners to improve the health and well-being of those affected.

The exploration of disability involved a cross-sectional survey using instruments based on the ICF framework including the Washington Group Short Set of Questions on Disability, the WHODAS-2, the WHOQOL-BREF and the EQ-5D. The objectives were to establish the prevalence of disability and the description of the impairments, functional limitations and participation restrictions of those identified with disabilities. A total of 950 households were visited in Oudtshoorn (a semi-rural town) and Nyanga (a peri-urban area) and information was gathered on 7336 individuals with a mean age of 30.5 years. The majority of the participants were women.

Both areas presented with estimates higher than those from the national census (5.0-6,7%). The urban area of Nyanga presented with a disability prevalence of 13.1% and the semi-rural area of Oudtshoorn with a prevalence of 6.8%. Overall the disability rate was 9.7%. The types of impairment and functional limitations were similar in the two areas, but more severe disability was reported in the semi-rural area, that also had significantly more elderly people.

Non-communicable diseases were identified as the major cause of disability in both areas, followed by communicable diseases in Oudtshoorn and unintentional trauma in Nyanga. However, a person was twice as likely to be disabled due to non-communicable disease (Odds Ratio 2.2) when living in Oudtshoorn, and three times more likely to be disabled due to intentional trauma when living in Nyanga (Odds Ratio 0.3). Non-communicable diseases were responsible for the largest number of healthy life years lost. Those living in Nyanga had a higher burden of disability due to their lower quality of life scores as measured by the EQ-5D.

Respondents in Nyanga consistently scored higher (worse) on all domains of the WHODAS-2 compared to respondents in Oudtshoorn. Living in Nyanga was associated with a 10% increase in domain scores. However, the pattern of scoring was similar and both areas reported worst functioning for the domains of Getting Around and Life Activities, which are associated with physical mobility. Respondents in Oudtshoorn reported better QoL and HRQoL than those in Nyanga. Functional level predicted the QoL scores, with Nyanga reporting worse functioning. Being employed and married was associated with a higher (better) EQ-5D VAS score, while mobility problems, pain or discomfort and anxiety or depression decreased the score.

Transport was the most commonly identified barrier in both areas. Major barriers for those living in Oudtshoorn were Surroundings and Help in the home, whereas Help in the home and Prejudice and discrimination were viewed as the major barriers for respondents in Nyanga. The elderly were the ones most likely to not receive the rehabilitation services that they needed.

The conclusions that can be drawn from this research are that context influences the experience of disability, and that disability prevalence alone is an insufficient basis for service planning. Those who experience greater deprivation also have a worse experience of disability. It is therefore essential for South Africa policy makers to view disability through a socio-political lens to ensure the equalisation of opportunities for people with disabilities. Improved quality of life for those living in under-resourced communities should be a priority. Service providers should have a broad range of skills to enable them to address not only the rehabilitation needs of people with disabilities, but also their social needs.

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Glossary of terms and abbreviations

ICF: International Classification of Functioning, Disability and Health

ICIDH: International Classification of Impairments, Disabilities and Handicaps

CBR: Community-based rehabilitation

PWD: People living with disability

HIV: Human Immunodeficiency Virus

AIDS: Acquired Immunodeficiency Syndrome

QoL: quality of life

HRQoL: Health-related quality of life

EQ-5D: EuroQol 5-dimensional questionnaire

GHS: General Household Survey

WHODAS-2: World Health Organisation Disability Assessment Schedule 2

WHOQOL-BREF: Abbreviated World Health Organisation Quality of Life questionnaire

DALY: Disability-adjusted life years

QALY: Quality-adjusted life years

UN: United Nations

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WG: Washington Group

WHO: World Health Organisation

Black African: refers to indigenous people of South Africa who speak an African language

Coloured: refers to people in South Africa of mixed ancestry - primarily includes Khoisan

White: refers to people of mainly European or Dutch ancestry

Apartheid: Legislated segregation on the basis of race

1 Introduction

South Africa is a country of great contrasts in terms of resources and health care availability. The limited health care resources in the public sector require that innovative measures are taken to adequately address the burden of disease, a concept which includes the impact of both mortality and disability on society. The Global Burden of Disease Report (2010) identified disability from disease and injury as a major issue for health systems, and queried the exclusion of disability as a central policy priority in the era of the Millennium Development Goals (6). It would appear that people living with disability (PWD) are not receiving the support that they need. The imperative of equitable service delivery requires that the special needs of PWD be taken into account. In order to plan appropriate services, these needs should be identified and quantified.

1.1 Background to the study

1.1.1 Prevalence of disability

The worldwide estimate of the number of people living with some form of disability is 1 billion, with approximately 190 million living with severe disability [1]. Disability prevalence is thought to be higher in low income countries due to the high burden of disease and the effects of poverty [2]. According to the World Bank, 20% of the world`s poorest people are disabled and are considered as most disadvantaged within their own communities [3]. Disability affects those who are vulnerable and is more prevalent among women, children and those who are impoverished [4]. Integrating the discussion of equity and disability prevalence will ensure that the services developed will benefit those most in need [5].

Although statistics have shown that approximately 10% of South Africans have disability [6], the recorded prevalence of people with disability in the general population has varied between studies [7, 8]. The 1996 National Census estimated the prevalence of disability to be 6.7%, while the 2001 and 2011 Censuses estimated a prevalence of about 5% of the total population [6, 9]. The General Household Surveys (GHS) conducted between 2001 and 2012, also by Statistics South Africa, indicated that the prevalence fluctuated between 2.4% in 2003 and

6.3% in 2010. Whereas some surveys found visual problems to be the most prevalent disability [10], the GHS found mobility difficulties to be the most common. These discrepancies in prevalence have been attributed to the mode of questioning and to systematic errors occurring during data collection in some cases [11]. These discrepancies in prevalence rates can have major implications on service planning.

The United Nations has promoted the Washington Group (WG) Short Set of Questions on Disability, which is based on the conceptual framework of the International Classification of Functioning, Health and Disability (ICF), as a method of standardising the collection of disability data [12]. Countries that have changed to using the WG questions have shown an increase in disability prevalence estimates [13, 14].

If data are to be useful for planning services, they must be relevant to the area in which the services are to be provided. The importance of context is emphasised by Trani and Bakshi (2008), who argue that prevalence rates can become obsolete if not discussed within their specific social and cultural context [15]. It is the contention of the authors that national census disability rates are not very useful in service planning as they may not reveal the specific needs of different communities. In addition, they may well under-report the prevalence of disability as compared to smaller scale surveys which focus on disability. It is argued that local prevalence rates are more useful to local planners, as the results can be utilised to directly target the causes and impact of disability within defined areas.

In the light of the discrepancies seen in the prevalence rates reported by the Census and the GHS within South Africa (which are both general surveys), a need to provide information on the nature and prevalence of disability through disability-specific surveys was identified. In addition, the information needed to be relevant to the local contexts in which the surveys were to be undertaken in order to provide local planners with information to target appropriate interventions.

1.1.2 Causes of disability – health conditions

In order to prevent disability, it is important to understand the health conditions that are associated with functional limitations. South Africa has a quadruple burden of disease which is compounded by historical racial inequalities. This burden includes life years lost and years lived with disability due to maternal and child mortality, the HIV/tuberculosis pandemic, non-communicable diseases and the rate of violence and injury, which is highest in poorer, previously disadvantaged communities [16]. It is anticipated that the global prevalence rate of disability will rise due to the increase in non-communicable diseases [17]. Advances made in

health care have resulted in reduced mortality, with many living with the disabling effects of disease. The longevity associated with improved health care further impacts on the disability prevalence, which is evident in high income countries where the elderly account for most of those having difficulty with functional activities [18-20]. In South Africa, the average life expectancy has risen from 58 years in 2010 to 61 years in 2014 [21]. We can therefore expect to see a rise in disability related to chronic diseases of lifestyle. A further major cause of disability in South Africa has been identified as injuries related to violence and motor vehicle accidents, compared to the major causes of death being communicable and non-communicable diseases [22, 23]. According to the US Centre for Disease Control and Prevention, people with disability are more likely to be obese (38%) compared to those without disability (24%), and are more likely to engage in risky health behaviours such as smoking and physical inactivity [24]. Disability itself seems to compound the problems and health conditions. In the Western Cape, for example, the large number of people with mental illness is reported to seriously impact the planning of community-based services for people with disabilities. People living with disability are also at a greater risk of unintentional injury such as violence, road traffic accidents, falls and burns. It is thus important to pay attention to the prevention of further disability and complications associated with disability [25].

If targeted strategies are to be put in place to reduce the prevalence of disability and to manage the health-related consequences, the health conditions that are associated with disability need to be identified. It is the contention of the researcher that these health conditions are not uniform across the different resource-constrained areas of the Western Cape and that different interventions might be needed in different areas.

1.1.3 Impact of disability

The researcher identifies with the WHO definition of health and the ICF framework of disability. Health is seen as more than the absence of disease, and disability is explained as the interaction between a health condition and the context in which it exists. Context thus becomes an important mitigating factor in the experience of health and disability. Many authors have suggested that poverty not only creates disability, but also perpetuates disability [4, 26-28]. This is because disability can be caused by malnutrition, unhygienic circumstances and lack of resources to access health care and other support services. Disability is perpetuated by the fact that people with disability in poor communities are the last to get decent jobs, will be overlooked for schooling in poor households and are very seldom empowered even in cases where their household income is better than those without disability [29]. Poverty in relation to disability has been dissected down to the inability to

maintain a certain standards of living, and does not only include economic measures. Relative poverty suggests a poorer level of living compared to the rest of society, where the standards achieved by some are comparably less than what is common in that particular society [4]. Most people with disability are likely to live in relative poverty, due to factors such as stigma and poor universal access. The impact of age and disability is a growing area of research in low and middle income countries, where there is rising life expectancy as a result of improved economies and health systems. In Nigeria, research has shown that older adults with disabilities do not have access to the assistance they need [30]. Women also seem to be more at risk of developing disabilities compared to men, with disability prevalence being much higher for women than for men [7, 13, 31, 32]. This may be due to the greater prevalence of nonfatal conditions such as arthritis among women [17]. The three main factors thus influencing the impact of disability appear to be context, gender, age and type of impairment.

1.1.4 Services available to people with disabilities

Internationally and locally, much has been done in the recent years to ensure the equalisation of opportunities for people with disabilities (PWD). This concept was brought to prominence by the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities [33]. The equalisation of opportunities is defined as the process through which the environment, services and information are accessible to all, including people with disabilities [34]. The United Nations Convention on the Rights of Persons with Disabilities came into effect in 2006, placing disability in a human rights framework and advocating for improved access to quality rehabilitation services for all [33, 34]. South Africa was a signatory to the treaty in 1997 and has placed disability on the agenda of development strategies through the Office of the Deputy President. The White Paper on an Integrated National Disability Strategy (NIDS) acknowledged the right of PWD to play a meaningful and participatory role in society. It allowed for the integration of issues affecting PWD into all government development strategies, planning and programmes [35]. Ten years after the publication of the NIDS, however, Maart et al. (2007) showed that PWD were still dealing with unmet needs such as inadequate access to public buildings [36]. The first World Report on Disability (2011) also acknowledged that PWD still do not have equal access to health care and are not receiving the services that they need [1]. There is thus a need to monitor the implementation of the White Paper with regard to environmental and health care barriers to accessing health care and other services.

In South Africa, the National Rehabilitation Policy acknowledges that rehabilitation services are inaccessible to the majority of people, even in better resourced areas such as the Western

Cape and Gauteng. In addition, most rehabilitation services are concentrated at tertiary institutions or provided by private service providers [37]. The 2030 Health Care Plan of the Western Cape Government includes strategies to counteract this and to provide rehabilitation services that are more easily accessible [38]. It accords well with the proposal of the WHO and UN, for countries to include home-based care in its social and health care systems [39]. In the Western Cape Province, the Comprehensive Service Plan for the implementation of Health Care 2030 described community-based services as those that complement the facility-based services by providing services within communities and also creating mechanisms through which communities can become aware of their health needs [38, 40]. This approach is aimed at empowering the community to participate actively in disease prevention and adherence to health programmes. Those providing the services will predominantly be generic community-based health workers and rehabilitation care workers. The fundamental premise of the Health Care 2030 strategy is improved efficiency and quality of care, and will therefore focus health interventions within geographic districts in order to have targeted interventions based on specific needs [38]. This directly relates to the purpose of this research, to identify the service needs of people with disabilities in two geographical locations.

Information relating to the specific needs of geographic districts in terms of the functional limitations of people with disabilities will be invaluable in informing the training curriculum of the generic community-based health workers envisaged in the Service Plan. Detailed information on the nature and extent of activity limitations and participation restrictions will enable the teaching of appropriate and relevant techniques of intervention and support.

1.1.5 Tools to identify and monitor the impact of disability

The ICF framework provides a globally accepted taxonomic classification of disability. This framework has been used extensively to categorise and classify impairments, functioning and participation across health conditions in a systematic and standardised manner [41-46]. Instruments using this framework were selected for use in this study. The WG Short Set has successfully been validated for use in South Africa and other countries to identify people living with disabilities [7, 14, 47, 48]. The WG Short Set can also be used to monitor the equalisation of opportunities for people with disabilities [49]. The 36-item WHODAS-2 has explicitly been recommended for estimating the burden of physical and mental health conditions and can also be used by clinicians to monitor change over time [50]. The six domains of the WHODAS-2 reflect the level of severity of disability, and enable the comparison of general disability and domain-specific disability across different health conditions [50]. The two above-mentioned instruments have been included, along with the WHOQOL, in the development of the Rapid

Assessment of Disability tool (RAD), and have been successfully validated for use in a developing country setting [51].

1.2 Rationale for the Study

The relevance of this study is rooted in the ongoing tension between available resources and the demand for inclusive and holistic health care. It is widely acknowledged that disability is a human characteristic which includes medical, functional and social perspectives, and should be presented in this manner to obtain a full view of needs [52]. The World Disability Report (2011) acknowledges that people with disabilities have greater health care needs and are excluded from mainstream priorities [1]. This could be due to a number of factors, namely the challenges faced in quantifying disability as well as the social and physical factors impacting on disability. Conventional methods for collecting population data on disability have relied on cross-sectional censuses and surveys that provide disparate information about prevalence rates. This information is often used by policy makers in the planning of rehabilitative services, with the inherent limitation that those who are not counted will remain invisible, and will not be able to achieve their full potential within society. The operational definition of disability within the context of this study, will be all people with an impairment or functional limitation.

An understanding of underlying diseases, injuries and the social determinants that cause and impact on disability is also considered critical in the planning of holistic services [53]. The scarce rehabilitation services in both rural and urban areas are being undermined by policies ignoring the high prevalence of disability associated with the quadruple burden of disease in South Africa. The Western Cape Department of Health has in its planning indicated the implementation of geographically designed health interventions [38]. This aligned planning fits well with the ethos of this research, that different geographical areas may require unique interventions.

Community-based intervention is not a new phenomenon in South Africa or the Western Cape [54]. The Home Community Based Care programme was prioritised as a cost-effective response substituting for a significant proportion of AIDS-related hospital care [55]. Further to this, the programme aimed to roll out the training of thousands of unemployed people as Community Health and Development Workers with skills that included the ability to identify families in need, advocacy, counselling, patient care and the provision of support related to HIV/AIDS and other chronic conditions, and to initiate and support income generating projects [56]. The fact that the two cadres of workers, community health workers and community

development workers, are linked to different government departments could make a holistic approach to patient care difficult. The aim of traditional community-based rehabilitation is for beneficiaries to have all their needs met through an organised approach. This would require that planners have a comprehensive insight into what disability entails in its nature, experience and political relevance. This study is therefore geared towards a holistic exploration of disability in two settings in South Africa. Although the concept and experience of disability has been explored qualitatively by several researchers [57-60], it is considered that a quantitative approach would provide more generalisable findings in a context where results need to be extrapolated to other areas. Bhagwanjee and Stewart (1999) advocated for research to result in the practical implementation of services that will positively influence the lives of people with disabilities [61]. The outcome of the study will thus be practical recommendations related to planning for contextually relevant services for people living with disabilities.

1.3 Research questions

The research questions that are addressed in this context are the following:

- What is the prevalence of disability in under-resourced areas in the Western Cape? It was expected that the prevalence of disability from small-scale disability-specific surveys would be higher than that reported by the Census and the General Household Survey.
- Is there a difference in the prevalence and pattern of disability between urban and semi-rural areas? Both areas are under-resourced so it was expected that the prevalence rate would be higher than the national average in both areas. Different patterns of disability would be expected in the two areas, however, due to the different demographic structures.
- What are most the common types of disability? This was uncertain in view of the conflicting results from previous surveys. It could be visual or mobility problems or even mental illness, which was identified by the Global Burden of Disease study as one of the greatest contributors to disability.
- What health conditions are related to disability and what is the “burden” due to disability for the most common conditions? Do health conditions differ in the two areas? It was anticipated that the two areas would differ in the causes of disability, due to demographic and contextual differences, with trauma being a more common cause in the urban area.

- What are the most common functional limitations? What is the relationship between disability domains and age? Although we have estimates of disability prevalence in South Africa [62], the major life domains affected have not been established. We expected a correlation between disability domains and the total WHODAS-2 score and age. The impact of context has been established before [36], and it was anticipated that the experience of disability across domains could be different in the two sites.
- What is the contribution of disability on health-related quality of life (HRQoL) and does this differ between the two areas? We were unsure whether previous results would be confirmed i.e. that place of residence was a determinant of perceived HRQoL such that better quality of life was reported by people with disabilities in rural areas [63].
- What environmental barriers and facilitators are experienced in the two areas? Is there a difference in disability profile between those who access services and those who do not? Do the urban and semi-rural areas differ? We were particularly interested in whether the service needs of people with disabilities were being met. We anticipated differences in the nature and quantity of environmental barriers in the two areas, with the urban group reporting fewer problems. We did expect service delivery to present a barrier in both areas, as difficulty in accessing health services has been highlighted in the World Disability Report [1]. We were unsure as to whether those who had accessed services would have more or fewer functional limitations. The most severely affected may be the first to receive services, but those who had received services might be functionally better off.

The study also examined whether the tools to monitor the impact of disability were reliable and valid when used in the Western Cape context.

1.4 Aims and objectives of the study

The overall aim of the study was to investigate and compare the prevalence, nature and impact of disability in two under-resourced areas in the Western Cape, one urban and the other semi-rural.

The specific objectives were:

1. To establish whether the prevalence and severity of disability, measured using the Washington Group Short Set of Questions on Disability, among persons living in two under- resourced communities are similar to the estimates from the National Census

and other household surveys. In addition, to determine whether there are any differences between the two geographical areas.

2. Using a convenience sample of people with disability, to identify which health conditions are responsible for the greatest "burden", as defined by Healthy Years of Life Lost due to disability, and to explore the health conditions that are responsible for different "burden" patterns in the two sites.
3. To identify the most common impairments, activity limitations and participation restrictions experienced by the sample of people with disabilities using the WHODAS-2, and to determine if there is a relationship between the impairments and the functional limitations.
4. To establish the determinants of the Health-Related Quality of Life (HRQoL) of people with disabilities using the EQ-5D and WHOQOL-BREF, and to determine the contribution of context and degree of disability on perceived HRQoL.
5. To compare the environmental facilitators and barriers experienced by people living with disabilities in the two areas, and specifically to determine whether health service delivery is a barrier or facilitator.
6. To test the validity and reliability of the isiXhosa and Afrikaans versions of the WHODAS-2 and WHOQOL-BREF.

1.5 Outline of the thesis

Two samples of respondents are described in this report. The first sample was identified through a community survey in which the person interviewed was asked to identify anyone in the household living with a disability. The second sample was formed by asking the people identified with disability to complete a questionnaire measuring the impact of disability. To minimise redundant descriptions of the survey methodology, this is described in a single chapter. Similarly, the description of the sample of people living with disability relates to the results of several chapters and is presented as a stand-alone chapter. For clarity, the results of each section of the questionnaire filled in by people with disabilities or their proxies are presented and discussed in different chapters, as relevant to each research question and associated objective. The structure of the thesis is thus:

Chapter 1 – Introduction.

Chapter 2 – Literature review of factors relating to disability. This chapter provides a background to understanding the historical and current philosophies related to disability and a review of the literature on aspects influencing the research.

Chapter 3 -Description of the methodology of the community-based surveys.

Chapter 4 – Results and discussion of the survey findings relating to the prevalence of disability.

Chapter 5 – Description of the sample of people living with disability who were interviewed. This chapter presents the prevalence of impairments and functional limitations, and describes the severity of disability as identified by the Washington Group questions.

Chapter 6- Results and discussion related to the health conditions associated with disability in the sample of people living with disabilities.

Chapter 7 – Results and discussion of the activity limitations and participation restrictions reported by people living with disabilities. This includes the results of the WHODAS-2.

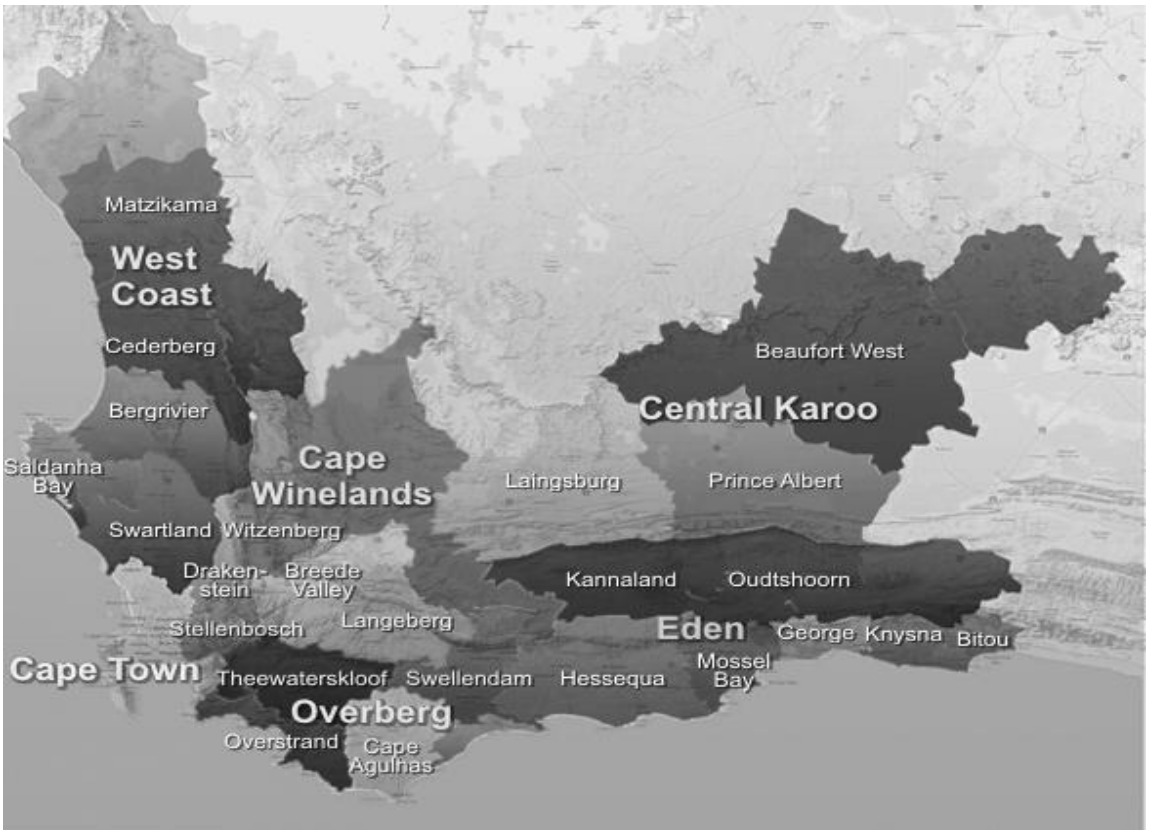
Chapter 8 – Results and discussion of the impact of disability on the quality of life of people living with disabilities. This chapter presents the results of the WHOQOL and the EQ-5D measures.

Chapter 9 – Results and discussion on the environmental barriers experienced by people living with disabilities, and access to certain services.

Chapter 10 – Post-hoc validation of the WHODAS-2 and the WHOQOL-BREF.

Chapter 11 – Discussion, conclusions and recommendations. This chapter summarises the results and conclusions of the different chapters, identifies the limitations of the study, presents final conclusions and makes recommendations regarding implications for service planning and further research.

1.6 Context of the research



The context of the research should be considered from a socio-political and geographical perspective. Socio-politically, the two areas were selected based on the framework of multi-deprivation as described by Noble et al. [64]. Townsend defines deprivation as the lack of basic needs, compared to poverty which refers to the lack of resources required to meet basic needs [65]. Noble et al. (2006) used the framework of Townsend (1987) to define multiple deprivations, using a robust methodology developed to identify areas of greatest need that would benefit from the reconstruction and development policies initiated post-democracy to improve the quality of life, and reduce poverty and social inequality among South Africans [66]. Five domains, comprising Income and Material Deprivation, Employment Deprivation, Health Deprivation, Education Deprivation and Living Environment Deprivation, were developed from the 2001 Census data to form an index of multiple deprivations for each province. Even though the Western Cape emerged as one of the least deprived provinces in South Africa, Oudtshoorn and Nyanga were identified as among the most deprived in the Western Cape [67], based on their deprivation scores of 363 and 420, respectively, from the National Multiple Deprivation Index Survey [64]. The higher the score, the more deprived the area.

1.6.1 Oudtshoorn

Oudtshoorn is a small town situated within the Eden District with a low population density. Seventy percent of the population described themselves as Coloured. Oudtshoorn has a low migration rate. Sixty four percent of the population has completed schooling (Gr 12), with financial constraint being the major reason for non-completion. Nine percent of the total Eden District population who reported having no income during the 2001 Census, resided in Oudtshoorn. Although this figure has improved in the 2011 Census, over 40% of the population had a monthly household income of less than R2000. The unemployment rate is estimated at 25%. The major health issues in Oudtshoorn are teenage pregnancy and the percentage of underweight births which is much higher than the national target of under 10% [68]. Child support grants made up 90% of the total grants assessed in Oudtshoorn, followed by the old age pension and the disability grant. Most of the residents of Oudtshoorn live in brick houses. The disability prevalence rate for the Eden district was estimated at 6.8% [62]. The Eden district has been identified as a pilot site for the implementation of National Health Insurance, with research of this nature being needed to inform service planning in this area. The strategic development objective of the Oudtshoorn municipality is to improve the quality of life of all its citizens, through inclusivity and a focus on job creation and social cohesion.

1.6.2 Nyanga

Nyanga is one of the oldest township areas in the Cape Town metropolitan area. It was created primarily for BIack migrant workers coming from rural areas, especially the Eastern Cape. The population is predominantly Black African. The employment rate is 55% among the age group 15-64 yrs. Only 31% of those aged 20 and older have completed Gr 12 or higher. Sixty seven percent of the population live in a formal dwelling. Approximately 18% of the population has no monthly income, however the mean income recorded per month is R3200 [69]. Even though the disability prevalence of the Western Cape is estimated at 5%, it is anticipated that Nyanga would have a much higher disability prevalence rate due to the high deprivation levels compared to the rest of the province. The major health issues in Nyanga are HIV/AIDS, tuberculosis and trauma (intentional and unintentional). The major risk factors include drug and alcohol abuse [70, 71]. The areas on the outskirts of Cape Town, of which Nyanga is one, have deprivation levels equal to most rural areas.

2 Literature review

2.1 Introduction

The need to quantify disability accurately, so that services could be quantified and appropriate measures put in place to target prevention strategies, has been a global challenge. While it is generally believed that the number of people with disabilities is steadily growing, especially in low and middle income countries [72], there is inadequate information about the prevalence and patterns of health conditions of people with disabilities. The understanding and conceptualisation of disability has also been noted as a major factor influencing the development of standardised methodology for reporting disability data [1]. This literature review therefore starts with a background to the evolution of the understanding of disability, and proceeds to explain conceptual frameworks used in disability research. The understanding and conceptualisation of disability has been suggested as a major stumbling block in achieving standardised data on disability. Finally, issues pertaining to the current study are reviewed. These include the quantification of disability and the nature of disability – which comprises the severity, the causes and the impact of disability, and the experience of disabling factors. Similar studies conducted in South Africa are summarised.

The electronic databases Academic OneFile, EBSCOHOST, Medline, PubMed, Cinahl and Google Scholar were used to source full-text articles. Library searches were done to source relevant books and unpublished theses. Only literature published in English or with English translation was included. There was no restriction on date of publication, but in most cases the latest publication was accessed.

2.2 Understanding Disability

According to Hammel (2004), the perspectives of disability are greatly influenced by disability activists, policy makers, academics, health and rehabilitation professionals, all of these having their own epistemological assumptions [73]. These assumptions are evident in their influence on the development of services, policies and legislation in relation to people with disability. The understanding of disability is also inherent in how society and policy makers influence the

experiences of people with disability. According to Oliver (1998), the understanding of disability has traversed from being seen as the sole responsibility of the person with a disability to a more inclusive approach, which is a socio-political issue rather than a medical one [74]. To understand the complex process of disablement, this chapter will explore the changing perspectives of disability by focusing on the traditional views, the individualistic medical approach, the social model of disability, and the biopsychosocial model presented by the ICF.

Historical terms used to describe disability have been mostly located within a deficits approach, and can be considered condescending and derogatory. According to Ngwena (2004) the terms of “idiots”, “retard” and “feeble-minded” for persons with mental disabilities and “cripples” and “handicapped” for persons with physical disabilities reinforced the view that disability is the sole responsibility of the individual, and also constituted labelling that was negative and socially tainted [75].

The model of ascribing a cause for impairments is evident in the religious model of disability, and the notion of bodily restoration as spiritual redemption appears essential to Christianity [76]. The traditional view that disability constitutes a form of divine punishment has led to the marginalisation of people with disabilities within their homes and communities. Maart et al. (2007), in a cross-sectional survey of urban and rural areas, found family attitudes to be a greater barrier in rural areas [36]. However, Ingstad (1999) found that the family value of the person with a disability was attributed to the contribution made to the household, i.e. the competence to perform tasks, and that the impairment itself was less important [77]. In some cases, the religious model has provided moral justification for the oppression and violation of disabled people`s rights. This is evident in the institutionalisation of people with disabilities and the lack of appropriate community services.

The Charity/Welfare model of disability is derived from the religious model. Most religions prescribe the giving of alms to those less fortunate to obtain absolution for oneself [78]. Coleridge (1993) criticises the model as it reinforces a superior versus inferior relationship, thus perpetuating the inequality of persons with disability[79] . The Welfare model is also evident in legislation and practices of creating quota systems for persons with disability in the labour market. The notion of ascribing negative connotations to disability could be ascribed to enlightenment, as well as the development of the society [80]. In countries where there is a poor understanding and negative inference of disability, the self-identification of disability could be misconstrued for social benefits or self-discrimination, thus resulting in unreliable data on disability.

Functionalism

Disability and the need for intervention gained prominence after the First Wold War, when mostly young men were sent home with impairments such as amputations, fractures, blindness and post- traumatic stress disorder [81]. It is also believed that this period gave credibility to the professions such as physiotherapy and occupational therapy, who now had the responsibility of restoring the “disabled” to “normal” so that they could either return to the frontline or prepare for post-war economy [81]. Amundson (1992) suggested that rehabilitation did nothing to address the environmental barriers that people with disabilities experienced but focused on preparing the individual to function in a pre-existing environment [82]. Barnes (1992), a disability rights activist, argued that the need for rehabilitation would be obsolete should the economic and social barriers faced by people with disabilities be removed [83]. Disability theorists also felt that rehabilitation professionals were protecting the status quo by medicalising and individualising problems that were socially created. The strong focus on normalising individuals with impairments in the functionalist model is viewed critically by disability activists, who question the claimed correlation between increased function and independence with perceptions of enhanced quality of life [73]. The interpretation of disability relative to what is considered normal functioning is subjective and varies across cultures and age groups. This approach would inadvertently exclude the elderly from being identified as disabled or as benefitting from interventions, since decreased function would be considered a normal progression of ageing. The disability prevalence rates seen in developing countries may be a reflection of disabled people perceiving themselves as having normal functioning, resulting in falsely low prevalence rates of self-report disability.

The concept of disability because of disease gained prominence much earlier than the above debate. Nagi (1976) introduced the concept of the disablement model following disease, using the four phenomena of disease, impairment, functional limitations and disability [84]. This model described the consequence of disease as it affects the functioning of an individual. According to Nagi, disability was not directly related to disease or impairment but was influenced by the social context [84, 85]. The WHO (1980) built on this model and included contextual factors in the disablement process.

Social Constructionism

The premise of social constructionism is concerned with the experience and meaning of disability, as constructed by the person with disability. Since the theory encompasses the holistic view of the individual and takes into account the context, it is closely related to the

social model of disability. These two concepts are used interchangeably within this paragraph. The ontology of this theory emphasises the removal of social and physical barriers in society and incorporates appropriate accommodations and support necessary for people with disabilities to function fully in society [86]. This model is further strengthened by the rights-based approach. The critique of the social model is that it completely ignores the impairment, which is integral to the lived experience with disability. Palmer and Harley (2011) suggests this as a possible contributing factor to the lack of disability-specific policy development [87]. The social-relational model, a refined version of the social model, acknowledges the contribution of impairments to the disabling process, but still proclaims that disability is dependent on the organisation of society [88, 89]. Using this model, interventions for people with disabilities would focus primarily on advocacy to improve access and on changing attitudes toward disability. Groce (1999) cautioned in that disability was socially constructed by the beliefs and values of society, e.g. if the emphasis was on strength, stamina and ability, those with physical impairments would either be marginalised or would benefit more from interventions than those who had mental or sensory impairments, and the opposite would apply if society instead valued intellectual abilities [90].

The heterogeneity of the models used to understand disability created major problems in responding to the needs of people with disabilities and in establishing the prevalence of disability. An urgent need for a more inclusive and acceptable framework for defining disability was necessary to make reliable international comparisons and to provide indicators for monitoring the rights of people with disabilities [1]. Kirby (2004) explores disability as a potential Universalist experience, whereby disability and the possible care requirements are viewed as life states and the experiences of all human beings at different stages of their lives. [91].

Positivism and Critical Theory in Disability

Disability explored in a positivist approach tends to focus on the inter-relationship of facts rather than experience. Initially, the measurement of disability was felt to be reliable using a positivist approach, where disability was measured only in relation to gender, age and race. The social approach within positivism, according to Oliver (1998), recognises the social context, the impairment and the disability [74]. The danger of proposing interventions for disability using pure positivism could result in interventions levelled at the individual rather than the context. Health care research has been dominated by positivist theories, focusing on cure and the improvement of function and participation within the context of good evidence [92, 93],

and should not be viewed as excluding the experience of people with disabilities. Critical theory seems to be the most appropriate theory to analyse the phenomenon of disability. According to Alderson (1998), critical theorists explore disability not as deviant from the norm, but as a collective with determinants in society and policy [94].

In summary, disability is a human characteristic that includes medical, functional and social perspectives [52]. Focusing on only one of these aspects of disability distorts the overall perspective of disability, as none of the three models is sufficient for identifying and describing disability. A more comprehensive quantitative description will be helpful, especially in planning for service delivery.

2.3 Conceptual Frameworks

The conceptual framework of the study is informed by the biopsychosocial approach to disability described in the ICF, as well as the universal values of social justice and human rights as equity issues when addressing services for people with disabilities

2.3.1 International Classification of Functioning, Disability and Health (ICF)

The ICF has its origins in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980) which was widely criticised for not acknowledging the influence of social barriers in disability (24, 25). The theoretical and conceptual underpinning of disability has evolved over the years, to be more inclusive of the diverse perspectives. The ICF framework (Figure 1) brings together the dichotomous conceptions of the social and medical models of disability. The medical model of disability relies on the naturalistic view that disability emanates from a biological impairment, whereas the social model defines disability as a socially constructed discourse. Thus the ICF aims to explain disability as the interaction of a person with a health condition with contextual factors such as environmental and personal factors as shown in Figure 1. [95]. The ICF framework allows the identification of a person with a disability not solely by a medical condition, but rather by their lack of functioning capacity on various domains. This could include limitations in basic activities such as walking, seeing or hearing and the extent to which these influence the person's participation in society e.g. working, attending school or other social practices. The use of these qualifiers allows assessment of the severity of the disability experienced. According to Ustun et al. (2003), the ICF framework can successfully be applied to a range of public health priorities such as functional profiling and intervention targeting [96]. Swanson et al. (2003) compared disability survey questions in five countries and found that the ICF framework supported international

comparability [97]. The ICF has been endorsed by the WHO as the international standard for describing and measuring disability [98]. Some disability activists perceive that the ICF reifies the deviance from "normality" [99, 100],[101], whilst others embrace the integrated model as a positive step in the right direction [102]. McDermott et al. have criticised the ICF for not meeting the criterion of parsimony, which was considered critical to epidemiological studies [103]. Although not accepted by all, the ICF framework has emerged as the discourse to achieve global standardised information about the various aspects of disability. It has been used in the development of instruments aiming to assess the prevalence and impact of disability, which forms the basis of the current study [12, 104], and is useful in positivist research on disability.

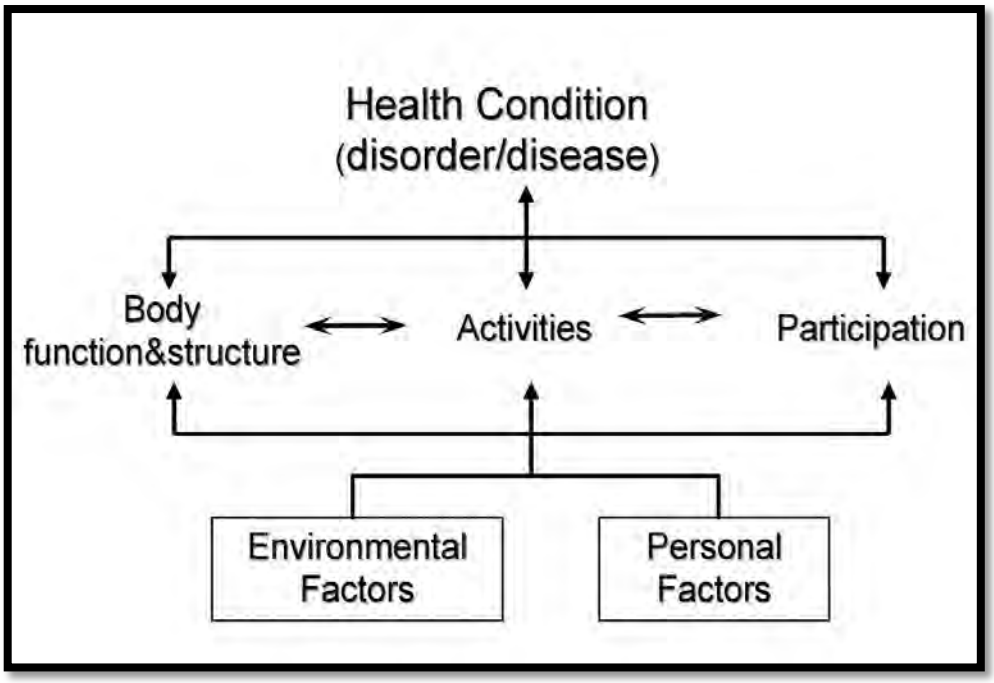


Figure 1: Diagrammatic representation of the ICF Framework [95]

2.3.2 Human Rights Framework

The notion of equalisation of opportunities for people with disabilities was defined in the 1982 World Programme of Action concerning Disabled Persons, as the process through which the general system of society, such as physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, are made accessible [105].The UN developments prior to the United Nations Convention on the Rights of Persons with Disability (UNCRPD), for ensuring the inclusion of

people with disabilities are commendable, but unenforceable. Countries that are a signatory to this treaty have the responsibility to show progressive realisation of the rights of disabled persons to full participation in society with reasonable accommodations. The convention calls for the strengthening of rehabilitation programmes by further training of staff working in rehabilitation services (Article 26). Health care services should be provided within the community and be of the same quality to persons with disability as to others (Article 25). The UNCRPD also provides articles that call for the international collection (article 31) and reporting (article 36) of statistical information on disability [34].

South Africa has endorsed the definition of disability as described in the UNCRPD, which in article 1 states, "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" [34]. However, the inclusion of core human rights concepts in the Rehabilitation Policy of South Africa was evaluated by Mannan et al. (2012) as being very poor [106].

2.3.3 Social Justice

Due to the discriminatory legacy within South Africa, inequality becomes an issue of social justice. Through the Office of the Deputy President (1997), South Africa developed the Integrated National Disability Strategy that outlined the principles of achieving the equalisation of opportunities for people with disabilities [35]. This strategy identified sectors within the disabled community that experienced comparatively greater levels of exclusion from the social, economic and political environment. These sectors require special targeting geared at redress of past inequalities and an understanding of their current needs. Within a democratic society, respect for others is instantiated not by recognition of their differences, but by their equality to others [91]. It is most unfortunate that 20 years post democracy, equality still eludes people with disabilities.

2.4 Quantifying Disability

Many factors influence the global prevalence of disability. It is estimated that the majority of those living with disability reside in low income countries [41]. According to the WHO and others, disability statistics consistently tend to show much lower disability prevalence rates for low and middle income countries compared to high income countries [1, 107]. Countries such as Australia, New Zealand and Canada presented disability prevalence rates in 2000 ranging from 18%-20%, whereas countries such as India, Mexico and Zambia obtained prevalence rates

ranging from 2.1%-14% [108]. Factors that have been identified as influencing the prevalence rate include the mode of questioning, the methodology utilised as well as the enlightenment of society [7, 13]. It has also been found that countries using an impairment-based focus compared to functional limitation focus, tend to record lower prevalence rates [2].

Historically most low and middle-income countries, including South Africa, used a dichotomous question when assessing for disability. People were asked, "Are you disabled?" It is likely that self- identification of being disabled is problematic in instances where being disabled infers upon you a new group identity. In countries such as South Africa where people with disability are considered a marginalised group, with specific benefits such as social grants, employment advantages and free health care, being classified as disabled usually requires fulfilling specific criteria. The historical regulation of group identity, e.g. race classification during Apartheid, would leave many folk, especially the elderly that have lived through Apartheid, apprehensive of identifying themselves as being disabled when an expert has not confirmed it. Marguerite Schneider (2008) has confirmed that people consider many factors such as access to health, culture, confirmed medical diagnosis and beliefs about functioning, when responding to the question "Are you disabled?" [55].

Loeb et al. (2008) showed that the mode of questioning affected the disability prevalence rate in a community-based survey conducted in Zambia, where the prevalence increased from 2.7% to 14.5% when moving from a dichotomous question to a capability approach [13]. In other countries, the question "Do you have a disability" with a yes/no response produced very low prevalence rates, e.g. Nigeria 0.5%, Philippines 1.3% and Ethiopia 3.8% [2]. Differences have also been seen in South Africa when minor changes were made to the disability question. Thus the disability prevalence rate from the National Census has ranged from 6.7% in 1996 to 5% in 2001 and 7.5% 2011 [6]. The 1996 question was based on a dichotomous response and asked whether the person had a s**e**rious sight, hearing or mental disability, where the level of severity was not clearly defined [11]. Many researchers have cited the use of dichotomous questions as a major reason for under-reporting of disability, especially in low and middle income countries [107-110]. The 2001 and 2011 Census used the participatory framework, asking whether the person had a serious disability that prevented them from participating in everyday life activities [6, 8].

Countries using the medical model, i.e. estimating disability prevalence from health conditions, have also reported very low prevalence rates, such as 1.8% in Palestine, 3.8% in Uganda and 5.7% in Hungary [2]. The critique of this approach is that many people might not know their

medical diagnosis, making under-reporting very likely. The Global Burden of Disease study, which also used a medical model, estimated a disability prevalence of 15% and considered it likely to increase globally due to non-communicable diseases [111]. Burden of disease is estimated from disability-adjusted life years (DALY) lost due to a health condition, which are calculated by generating preferences for health states – initially using expert opinion but more recently through qualitative interviews with individuals [112]. The World Report notes that particular attention was paid to the internal consistency and comparability of estimates across specific diseases, causes of injury and distribution of functional limitations, but the major limitation of the burden of disease estimates (and other estimates based on the medical model) remains the exclusion of contextual data [1]. The disability prevalence from the Global Burden of Disease study and the World Health Survey are very similar, even though the studies used different methodologies and conceptual frameworks of disability.

The Word Health Survey, using a standardised methodology in 59 countries, estimated the prevalence of disability among those older than 18 years to be 15.6% [113]. It further reflected the differences between low income and high income countries with the prevalence rates being 18% and 11.8%, respectively. The World Health Survey used the ICF as its conceptual framework and in the development of its functioning domains [96]. The responses to difficulties in functioning were graded from no difficulty (0) to extreme difficulty (100) and a threshold score of 40 was set as the disability estimate to identify those as having difficulties in their everyday lives. A threshold of 50 identified those with significant difficulties, indicating severe disability. The mean prevalence for severe disability was estimated to be 2.2% [1, 114], which is very similar to the prevalence rates obtained in most low income countries. This could suggest that in low income countries, only those with severe functional difficulties tend to be identified as being disabled. This is supported by Schneider (2009) who found that South Africans with severe difficulties in functional activities were more likely to identify themselves as being disabled [7].

Disability prevalence estimates are also influenced by the thresholds set for disability, which could also be defined as the operational definition of disability. The World Health Survey has set the threshold at those identifying “some difficulty” in at least two domains, or “a lot of difficulty” in at least one domain [96].This criteria was also used by SINTEF in their Levels of Living Studies conducted in Mozambique, Malawi, Zambia and Namibia [13, 48, 115, 116]. The Mozambique study showed that disability prevalence dropped from 5% to 3.8% when the criteria were more stringent [14]. The Washington Group has set the disability criteria as having “some difficulty” in at least one domain [117]. When this was used in Zambia, the

disability prevalence for those with “some difficulty” was 14.5%, and those with “a lot of difficulty” in at least one domain was 8.5% [13]. Disability prevalence rates in the 2011 Census are presented as a disability index that includes individuals with moderate to severe disability, i.e. presenting with at least some problems in at least two domains or moderate difficulty in one domain. These cut-offs have been used in various settings and can affect disability prevalence depending on how lenient or liberal they are.

Enlightenment and cultural beliefs further impact on the response given to questions about disability. Stone-MacDonald showed that traditional views held in Tanzania resulted in many people hiding their children with disabilities [118]. Enumerators conducting the 2011 Census in India received special training on how to ask disability questions in a diplomatic and sensitive manner to accommodate respondents who were embarrassed to identify themselves or family members as being disabled. India tends to canvass their disability questions prior to the census so that the population is more comfortable in responding. However, India has recorded a disability prevalence of 1.8%, even lower than South Africa [119].

Disability prevalence estimates are not consistent within countries, and differences have been found between estimates from the national census and smaller scale community-based surveys. The smaller surveys are considered to produce more reliable disability data, since the questions are targeted toward disability and the questionnaire is completed by the person affected [120]. Census data on disability are usually limited and are completed by one person on behalf of the household. Even though not every household is enumerated in a survey, the sample selected must be representative of the population. Household surveys in South Africa have produced higher prevalence rates, except for the 2007 Household Survey [10, 121], which canvassed households across all 9 provinces and estimated disability prevalence at 4%. The lower disability prevalence rates could be due to the systematic errors observed in the data, which included a shortfall of women aged 20-34 years in some provinces, uneven distribution across provinces and an excess of those aged 85+, particularly among men [11].

Madden et al. (2013) have reaffirmed that the collection of information about people with disabilities should be aimed at improving services, rehabilitation, policies and the quality of life of those affected [122]. Census data have been deficient in estimating disability prevalence and could jeopardise the effective and efficient planning of services for people with disabilities unless other information on the *nature* of disability is also considered.

2.5 Nature of Disability

For the purpose of this thesis, the nature of disability encompasses the major causes of disability, its severity and types of impairments and functional limitations, and the impact on individuals with disability.

2.5.1 Causes of Disability

The major cause of disability around the world has shifted from infection to lifestyle choices. Global policies can inadvertently influence the health transitions experienced in many poorer countries [123] by affecting the resources available to people to make health choices. Due to limited resources, poorer communities are unable to afford healthy foods and access to health care. Poverty has also been found to be a causative agent of mental illness [124], which together with other physical impairments adds to the perception of being disabled [125].

Infectious diseases still appear to be the major cause of disability among children in low and middle-income countries [126, 127]. According to Lansdown (2002), the root of childhood disability is poverty, with many children being disabled as a result of poor nutrition, lack of resources to access health care, and parental illiteracy [128]. The “dop” system (where wine was used as payment) and the poverty of commercial farm workers in the Western Cape South Africa have resulted in a high level of children with stunted growth and developmental problems [128]. In 2004, the World Bank estimated that 80 million Africans were disabled with the causes primarily linked to consanguinity, conflict, poverty and HIV [29]. The preventable causes of childhood disability lead to increased prevalence of disability in adulthood.

The current major global causes of disability among adults have been listed as musculo-skeletal conditions, diabetes and mental health conditions [111]. Further to this, road traffic accidents accounted for almost one-third of the world injury burden [111]. The UK burden of disease study (2010) has shown cardiovascular disease, chronic respiratory disease and neurological conditions as the primary contributors to the burden of disability among those aged 80 years and over, compared to musculo-skeletal conditions and mental and behavioural conditions in the UK general population [129]. Elderly with multi-morbidity were more likely to be disabled if existing diseases were paired with dementia [125].

The major causes of disability in South Africa have been identified as trauma and non-communicable diseases [130]. The changes in dietary and lifestyle patterns associated with the economic and demographic transition in low and middle income countries have been blamed for the increased prevalence of chronic diseases of lifestyle [131]. South Africa has the highest prevalence of diabetes and hypertension in Sub-Saharan Africa [132] and the major disabling impairments associated with these conditions are blindness, amputations and partial paralysis

from cerebro-vascular accidents [133]. In the Western Cape, the major causes of disability are mental health conditions and trauma related to accidents and violence [16, 22, 134]. Substance and alcohol abuse are contributing factors to the this high burden of trauma and mental health conditions [16].

The longevity associated with increased medical advancement and technology allows people to live longer with chronic health conditions in addition to the general effects of the ageing process. In high income countries, the disability profile includes more elderly women whereas disability varies significantly between age groups in lower income countries [96],[121]. Women tend to be more prone than men to developing age-related functional limitations in both low and high income countries [27, 41, 113, 135, 136]. In some countries, men have higher disability rates than women in the younger, economically active years, with the main cause of disability being trauma [31].

2.5.2 Severity and type of impairment and functional limitations

The first disablement model distinguished between functional limitations and activity restrictions, with the former related to bodily functions, and the latter to a person's functioning [84]. Functional limitations are seen as a direct consequence of an impairment, and are not dependent on environmental factors, whereas activity restrictions are correlate highly with the context of the individual [137]. Functional limitations are common among the elderly and are not always associated with functional difficulties, especially where support and appropriate assistive devices are readily available [138]. While cognitive limitations and functional limitations involving the lower limbs tend to reduce functioning, hearing difficulties seem not be associated with poorer functioning [139, 140].

There is usually a correlation between the level of severity of a condition and the consequent disability experienced, as well as the probability of receiving care [141, 142]. The severity of disability is a known indicator for accessing social support services and is significantly correlated with poverty [29, 87]. Health expenditure is also a significant economic burden for those with severe mobility problems compared to those with severe mental disabilities [87]. In most measuring instruments, severity of functional limitation or participation restriction is graded on a continuum from mild to severe, or by using a scale from 1-5, with 5 being most severe/cannot do [13, 49, 143]. This type of grading provides a global score of disability, suggesting the inter-relationship between activity limitations and participation. Functional limitations do not necessarily impact on participation if support structures are available to moderate the effect of the limitations [139, 144]. Similarly, associated medical conditions or

impairments were not directly related to functional limitations [145]. However, those with limited resources seem to be differentially at risk of experiencing greater restrictions in participation [146]. The perception of severity of disability has also been found to be influenced by culture and gender. Women were more likely to rate their disability as severe compared to men [147, 148]. Merrill et al. (1997) found that women reported worse functioning than men, but also performed worse on functional activities compared to men, and concluded that both genders reported their level of disability accurately [149]. Except for the domain of communication, the prevalence of mild to moderate disability across all impairments as measured by the WG Short Set was highest among women in the last census completed in South Africa. [62]. This census also showed that severity and type of disability were closely related to employment, where individuals with visual difficulties were more likely to find employment than those with other impairments or functional limitations [62].

Visual impairment is the most prevalent preventable functional limitation at a global level [150]. While this also emerged as the most prevalent type of impairment from the South African annual census [8, 9, 31], household disability surveys found mobility impairments to be the most prevalent [121]. Visual impairments appear to be more likely to be the most prevalent limitation in low and middle-income countries. Thus Rwanda, Zambia, Malawi, Zimbabwe and Mozambique have also recorded the highest disability prevalence rates among people with visual problems [13, 14, 27, 32, 116]. South Africans with mild vision impairments were more likely to live in rural and traditional areas, whereas those with severe visual difficulties were more likely to live in urban areas [62].

Due the large ageing populations in higher income countries, mobility impairments are the most prevalent type of impairment in America, Canada and UK [151]. Mobility problems are also most prevalent among the elderly and the wealthier population groups in South Africa [62]. Disability measured among the elderly across different cultures using the WHODAS-2 has shown that most elderly tend to have problems within the domains of Getting around, Life activities and Participation in Society [147, 148, 152]. These domains seem to be more influenced by functional limitations associated with walking. Other than ageing, mobility problems are also the result of trauma and complications from non-communicable disease such as diabetes and stroke, and are likely to increase globally.

2.5.3 Impact of Disability

The impact of disability refers to the factors that influence the experience of disability. For the purpose of this literature review, these factors include attitude, employment, environment, gender and quality of life.

Qualitative interviews in Mozambique showed that disability and impairments of hearing, seeing and mobility were attributed to superstitious beliefs, and that disability was believed to be contagious [14]. Similarly in South Africa, being bewitched was a suggested cause for epilepsy [153] . These beliefs rooted in the historical understanding of disability have major implications for the societal barriers faced by people living with disabilities. In societies with strong superstitious beliefs, parents with disabled children are ostracised, leaving families isolated and excluded [154]. The children tend to be hidden and have no opportunities for participating in community or family activities. Children with disabilities have also been marginalised in poor families, as resources would rather be spent on non-disabled siblings. This can leave the disabled child malnourished and without education [4].

The 1998 Employment Equity Act 55 in South Africa supports the affirmative appointment of people with disabilities, and this could explain the small difference in unemployment rate between people with and without disability reported in the 2011 Census [62]. The current unemployment rate in South Africa is estimated at 27.5%, with the Western Cape Province at 21.6% [31]. The unemployment rate among people with disabilities was estimated at 27.6% [62]. Unemployment was found to be highest among rural and traditional areas, and among Black Africans [31], who were systematically marginalised due to the Apartheid policies, with limited access to education, employment and access to health and welfare services [155]. Although, people with disabilities of all races experienced discrimination due to the medicalisation of disability, the effects of the Apartheid system are still evident in the unequal distribution of wealth across races [112].

The economic impact of disability is somewhat ameliorated by the social grant in South Africa, but this seldom enables families to get out of the poverty cycle created by disability. In situations where the majority of the population lives in relative poverty, advancement of people with disabilities is seldom achieved as they have to compete with the broader society in a context of limited resources [156]. The HIV pandemic created a steep increase in those receiving a social grant, leading the government to rethink its allocation and to seek ways of integrating people into the formal labour market. Efforts for the inclusion of people with disabilities included the Expanded Public Works Programme, which is an employment creation

programme for vulnerable groups. This programme failed to achieve its target of including 2% of people with disabilities, however [156]. Supported employment has been advocated for the economic empowerment of people with disabilities, and has been especially effective in integrating people with mental disabilities into the labour market [157-159]. Vocational education and training was recognised as a key factor for the inclusion of people with disability into the small enterprise sector [35]. However, the vocational training programme was criticised for not providing people with disabilities with sufficient skills to enter the labour market [156]. Without equal opportunities for development and a barrier-free society to promote social justice, people with disabilities will remain at the periphery of society.

Wiman et al. (2002) estimated that 85% of people with disabilities experienced barriers in the form of others' attitudes, access to resource information and transportation [160]. A study conducted in India showed similar results with on average 50% of people with disabilities reporting social exclusion, difficulties in accessing transportation and information, and discrimination from others [161]. Maart et al. (2007) showed that people with disabilities living in an urban area in the Western Cape perceived more barriers with the physical environment than those living in a rural area (particularly access to public buildings), whereas those living in a rural area experienced more barriers with regard to attitudes [36]. The lack of communication between programmes, government departments, organisations for people with disabilities and civil society is a critical factor limiting the prioritisation of issues affecting people with disabilities [156].

People with disabilities are not a homogenous group, with differences across disability type, but women appear to be more affected by disability than men. It has been said that disabled women experience a double prejudice, firstly as women, and then as a disabled person [162, 163]. In patriarchal societies women are considered subservient to men, and disabled women who are unable to fulfil society`s expectation of womanhood are valued even less [35]. The discrimination experienced by women or disabled people in their communities has also been linked to their ability to contribute meaningfully to the household. Women with disabilities are less likely to find employment compared to their disabled male counterparts, and should they find employment, will receive a lesser wage [163]. Women with physical disabilities have been shown to experience similar levels of domestic abuse compared to non-disabled women, however women with disabilities face domestic abuse over longer periods compared to non-disabled women [164]. It will therefore be necessary to focus especially on the needs of women when planning services for people with disabilities.

Quality of life (QOL) and health-related QoL (HRQoL) have become important measures of outcome in determining the efficacy of health interventions, as physiological measures correlate poorly with the individual's expectations and aspirations [165]. QoL is a measure of a person's expectations and aspirations within a specific context. HRQOL refers specifically to the impact of disease and disability on perceived quality of life, or those aspects of quality of life that are amenable to health interventions, and can be different for two people with the same health condition or disability [166]. Recent research in South Africa among children and adolescents has shown that the severity of disability is not predictive of perceived QoL [167]. However, in studies among the elderly and in a socially and culturally diverse community in South Africa, QoL was predicted by gender, geo-locality and socio-economic status [147]. Poorer QoL was found for women, people living in a rural area, lower socio-economic status and people with no formal education [147, 168-170]. The elderly in South Africa were more likely to report better QoL than their counterparts in Uganda [171]. The data for high income countries is somewhat different, with more elderly reporting high levels of satisfaction and well-being [168]. This has led authors such as Chappell (2010), to suggest that by limiting dependence due to disability, the negative impact on QoL can be minimised or eliminated. She further suggests that an environment that conforms to universal design and encourages independent living will alter the perceived quality of life of people with disabilities [168].

The themes that emerged in a Brazilian qualitative study that explored perspectives on QoL among people with disabilities related to work, leisure, social inclusion, education, universal accessibility and integration in society [172]. When exploring QoL among Afrikaans-speaking people in South Africa, the major themes that emerged were the impact of health conditions, participation in society (especially religious activities) and functioning [173]. The domains most valued by isiXhosa-speaking people living in an under-resourced area were owning a brick house, access to health care, availability of food and family safety [174]. Jelsma et al. (2008) concluded that people living in under-resourced communities were unable to differentiate between HRQoL and general perceived QoL, as they conflated issues of socioeconomic and service delivery with perceived state of health [174].

2.5.4 The Determinants of Disability

Disability cannot be explored without consideration of the determinants of disease, as disability is a major outcome of poor health. Mayosi and Benatar (2014) aptly suggest that the response to the major challenges of continued and increased prevalence of infectious diseases and non- communicable diseases must be to address the social determinants of health [123]. Most of these determinants are historic and lie outside the ambit of the health system. Many

factors contribute to the development of disability, and this paragraph will explore risk factors for the development of primary and secondary disability.

The most pressing of the determinants is poverty, which leaves many households short of resources to make healthy lifestyle choices. The cycle of poverty and disability has been well described, with emphasis on the exclusion of people with disabilities from the workplace and society and how it eventually leads to poverty [4, 29, 175, 176]. According to Mitra (2013), disability is associated with low educational levels, higher unemployment rates and high health expenditure that create a multi-dimensional poverty [177]. A large proportion of people living in South Africa experience poverty with limited access to clean water, housing, education, proper nutrition and employment [123, 178]. The lack of these basic amenities sets the scene for poor health, disability and shorter length of life in both rural and urban areas [123]. Limited financial resources restrict the capacity to buy healthy foods, to access public transport and to attend clinics or health services. Without access to appropriate health services, secondary disability cannot be prevented and the onset of disability for those with chronic diseases of lifestyle will be accelerated. The influence of unemployment also has major social consequences, and has been seen to fuel gangsterism and drug and alcohol abuse in low socio-economic communities.

With larger cities being the major hub of economic activity, the influx of employment seekers create unfavourable living conditions in areas that do not have capacity for suitable housing and sanitation. According to de Hollander et al. (2003), lifestyle is determined by the social environment. Community safety, social cohesion and quality of life are primarily determined by the quality of the environment [179]. Rapid urbanisation has been associated with urban poverty, particularly in informal settlements, resulting in poor health conditions and a lack of environmental amenities [180].

South African cities have experienced rapid urbanisation in the past 20 years following the end of Apartheid, with more people moving to the cities for employment. The inability of cities to cope with this influx has resulted in many people living on the outskirts of town, far from amenities and in squalid conditions [180]. The urban transition is also associated with lifestyle changes for a primarily rural population, placing them at risk of developing diabetes due to diet changes that are high in fat and sodium [181]. Poor diet has been directly related to obesity and the early onset of type 2 diabetes in adults and adolescents. Diabetes contributes approximately 78,900 life years lost due to disability, and is anticipated to increase due to increasing urbanisation [133]. The neo-liberal trade and economic policies have given greater

access to transnational foods, which are usually cheaper but less nutritious [180], and have caused job losses in the manufacturing sector, as goods can be manufactured at lower cost in other countries.

Apartheid systematically disadvantaged Black and Coloured population groups in South Africa by limiting access to education and employment opportunities, thus placing them at risk of poverty and eventual disability. In a longitudinal study conducted by Williams et al. (2012) over a 20-year period, ethnicity and socio-economic disadvantage emerged as risk factors for disability [182]. Certain ethnic groups are more prone than others to develop specific diseases, which places them at a greater risk of eventual disability. UK population groups with Indian Asian descent experience higher rates of heart disease compared to Europeans [182]. Similarly in South Africa, Indians and Black Africans have the highest prevalence of diabetes, which also places them at risk of eventual disability [181]. Ethnicity, confounded by socio-economic disparity, has consistently emerged as a risk factor for experiencing greater risk for disability (92). Hosseinpoor (2013), confirmed that disability prevalence was much higher among the poorer populations (those with lower wealth quintiles) within countries and across countries, when adjusted for age. His results further showed that that approximately 1 in 3 adults within these lower quintiles was disabled in South Africa [5].

Ethnicity is also more correlated with deprivation than with monetary poverty in South Africa [178]. Deprivation according to Rawls, cited in Noble (2001), refers to the lack of "basic goods/capabilities" that cannot be bought, because they are not provided by the System [183]. Klasen (2000) found that poverty was distributed differently by race, residents and household structure, where those most deprived were Black African and living in rural areas [178]. This would support the fact that disability is more prevalent among Black Africans coming from rural areas [31].

2.6 Studies conducted in South Africa

"We also count!": The extent of moderate and severe reported disability and the nature of the disability experience in South Africa [121]

The "We also count!" (1996) CASE study explored the nature of the disability experience in South Africa in the 20th century [121] using a similar methodology to the current study. A cross-section of the population weighted for race, gender, age, and urban and rural areas was sampled across all provinces. Information was gathered on 42,974 individuals and yielded a disability prevalence of 5.7%. The most common activity limitations were in movement and

activities of daily living. The Western Cape had a disability prevalence rate of 3.8%. Black African respondents living in urban areas were more likely to have a disability than their rural counterparts were, but respondents in rural areas were more likely to report multiple impairments, which could suggest the lack of services to prevent minor impairments from developing into severe disabilities. This survey also found that White children aged 6-10 years were more likely to report a disability than the other races, and implied that this could be due to them having better access to maternal and child health services which allowed them to survive childhood illnesses and trauma. The majority of those interviewed attributed the cause of their disability to illness (26%), with the most common illness being high blood pressure. The authors of the CASE study assumed that those who did not know the cause of their disability could have acquired it at birth or it could be due to a lack of services for appropriate diagnosis; however, 21% could relate the cause of their disability to incidents before and during birth. Accidents and violence were the most noticeable cause of disability for respondents aged 19-50 years. Health services (particularly rehabilitation services) were listed as most needed and the most received by the respondents, and educational and welfare services were the least received. Access to services was influenced by the ability to pay for transport or for the service needed. The study concluded that the experience of disability is worst for Black Africans living in rural areas.

The CASE study included a qualitative component to explore the personal experience of disability. The themes emerging from the focus group and case studies referred mostly to access to services, employment and attitudinal barriers. Black Africans felt doubly disadvantaged being black and disabled, with services being more readily available to their white counterparts. Examples provided were the internationally trained sign language interpreters for the Whites, with no or limited access to sign language interpreters in Soweto. Barriers were explored quantitatively in a survey conducted among people with disabilities living in an urban or rural area, and attitudinal barriers were found to more prevalent among family members for those living in rural areas, and among health assistants for those living in an urban area [36]. People with disabilities in both rural and urban areas identified barriers to services related to employment and education as most prevalent.

The prevalence of locomotor disability and handicap in the Cape Peninsula [184]

A cross-sectional door-to-door survey was conducted in Nyanga, Fish Hoek and Bishop Lavis as part of a three-part survey exploring the prevalence of locomotor disability in the Cape Peninsula. In Nyanga, 268 dwellings were visited and information obtained on 2072 Black

Africans. The crude disability rate was 18.3/1000. There were similar proportions of elderly and economic active disabled people in the sample. Most people stated that the disability was due to illness, including poliomyelitis (21%) and cerebrovascular accident. The majority of people with disability used a walking aid, tripod, stick or frame. The author noted that the results confirmed previous findings where disability prevalence varied in relation to social class, but cautioned that the results could not be interpreted in relation to an urban context, as the Nyanga population are primarily migrants from the rural Transkei and Ciskei. Unemployment was low, with 76% on permanent disability grants.

In Bishop Lavis, the survey was carried among 9112 people, and the disability prevalence rate obtained was 11.2/1000. The main cause of disability was illness and trauma. The descriptors for illness were cerebrovascular accidents and poliomyelitis. Disability was most prevalent in the age group 16-59 years (57%) and 15% of those with disabilities were employed.

The survey among 2391 Whites in Fish Hoek yielded a prevalence rate of 13/1000. The main cause of disability was illness, with most people identifying it as arthritis. The highest disability prevalence was in the age group 60+ and many of the elderly employed a personal helper. Fifty percent of those within the working age group were employed. Disability was more severe in the Fish Hoek population than in the other two sites.

2.7 Instrumentation

Valid and reliable measuring instruments are essential for effective research, and especially so in the area of disability where the epistemologies have been so historically diverse that cross-cultural comparisons are difficult. The methodologies and instruments used to explore the concepts of disability have been developed in the various frameworks described previously in Chapter 2. The instruments selected for the current study were chosen because they are conceptualised within the ICF framework, which has been recommended as the standardised framework for understanding and exploring disability thus allowing meta-analysis of data from various studies [1]. The instruments were selected to identify persons with disability, to assess their activity limitations and participation restrictions, and to assess their perceived QOL.

The need for valid and reliable instruments has been expressed by the UN and the WHO with an emphasis on cross-cultural validity and reliability [1]. It is important during the translation of instruments to ensure that the original construct and meaning of the instrument is maintained. As the WHO has developed most of the instruments used, the translation process described by the WHO was followed.

In addition to using these standardised instruments, the current study included a self-developed questionnaire to obtain demographic information and to explore access to needed health services and the potential barriers experienced.

2.7.1 Reliability

Reliability of an instrument refers to its ability to produce the same score when measuring an unchanging value, or to what extent the instrument produces equivalent results for repeated trials [185]. In simple terms, it is to what extent the instrument is able to consistently measure what it is intended to measure. Reliability of an instrument can be evaluated as internal consistency, which measures the constructs of an instrument, and as test-retest reliability, which refers to the timing and context of administering an instrument [185].

Test-retest reliability is related to intra-rater reliability, which assumes that the context is constant between measures, and inter-rater reliability, referring to consistency obtained between the measures taken by different individuals.

The internal consistency of an instrument is estimated by calculating the Cronbach`s alpha, also termed the co-efficient of reliability, which is calculated through item correlations [186]. Correlations (r or $r^{2)}$ have been suggested to be an appropriate measure of internal consistency when the possibility for error is low [186]. A Cronbach`s alpha of ≥ 0.9 is considered excellent, $0.7 \leq \alpha < 0.9$ good, $0.6 \leq \alpha < 0.7$ acceptable and $\alpha < 0.6$ poor. Instruments are considered reliable if they show a Cronbach`s alpha of at least 0.7 [185]. A more comprehensive measure for estimating internal consistency is item analysis, which measures how well items within an instrument correspond to each other, as well as to the instrument as a whole. This allows the researcher to remove items that do not provide useful information, or that confuse data [185, 187]. Cronbach`s alpha can be high even if the item inter-relatedness is low [188].

2.7.2 Validity

Internal and external validity refer to the validity of the research design as it attempts to establish a relationship between independent and dependant variables within a high degree of certainty [185]. Validity also refers to how well the instrument measures what it intends to measure and how well the results reflect the intended outcome of the study [189, 190]. External validity refers to the ability of reproducing the study within a similar context. Internal validity can be assessed using different approaches namely criterion validity, content validity, construct and face validity [185, 190].

2.7.2.1 Criterion validity

Criterion validity is established by testing a new instrument against an existing valid instrument [185]. The new instrument is considered valid if it produces similar results to the validated instrument. This measurement is also known as testing the concurrent validity. Predictive validity, another measure of criterion validity, seeks to measure the ability of an instrument to predict an outcome [191]. Criterion validity is measured using a correlation co-efficient, where a high correlation co-efficient would indicate criterion validity [191].

2.7.2.2 Content and Face Validity

Content validity ensures that the instrument measures what is intended to be measured. Content validity is usually established by asking a panel of experts in the topic to review the instrument and its items [191]. Face validity can be measured by testing the instrument on the intended participants, to ensure that the level of complexity is appropriate for the sample [185].

2.7.2.3 Construct Validity

Construct validity refers to the items within an instrument being clearly related to the associated theories underpinning its development[191] . An instrument would have construct validity when it gave similar results to other instruments measuring a similar construct/theory. Construct validity is measured using a correlation co-efficient that is obtained by exploring the method of confirmatory factor analysis [192]. Confirmatory factor analysis has been proven to be a useful tool for assessing convergent and discriminant validity [193]. Construct validity is of specific interest when using translated instruments, or when testing an instrument across different cultures.

2.7.3 Washington Group Short Set of Questions on Disability

The WG Short Set was used to identify persons with disability, and to establish the prevalence of disability in the two geographical areas, i.e. the number of people who said that they experienced difficulties with activities.

The Washington Group on Disability Statistics (WG) was formed following a United Nations meeting held in New York that declared the need for more reliable and comparable international disability data [12]. Through a consultative process, a short set of six questions based on the ICF were developed and tested in 15 countries. Cognitive interviews were used in these studies to examine the questions for response bias [194]. The six questions were thought to encompass universal levels of functioning that were not necessarily influenced by culture, but were able to “identify most people with difficulties in functioning in basic actions that have

the potential to limit independent participation in society"[12]. The questions ask about difficulties experienced with functional activities such as seeing, hearing, walking, self-care, remembering and concentrating, and communication. Respondents are required to list the difficulty using a 4-point scale where 1 = no difficulty, 2 = some difficulty, 3 = a lot of difficulty and 4 = unable to do. The questions on seeing, hearing and walking have been successful in identifying people with sensory and physical disabilities. Countries such as South Africa and Mozambique have seen high prevalence rates of visual difficulties when using the WG questions [31, 115]. The questions on self-care are said to identify those with upper body limitations. A major criticism of the WG questions is that they have the potential to miss people with mental health problems. The WG has acknowledged this, but has suggested that those with mental health or psychological difficulties could potentially be identified by the questions related to communication, remembering and concentrating.

South Africa was one of the countries that participated in the development and testing of the WG questions. Marguerite Schneider (2009), the South African representative of the group, found that more people in South Africa were able to identify themselves as having difficulties using the WG questions, that ask about difficulties with functional activities, than when a dichotomous response for disability was used [7]. The WG questions were found to be valid and reliable for use in South Africa, and have since been used in the 2011 Census [10]. The WG Short Set has been used in various other studies to establish disability prevalence, in conjunction with other questions, or slightly adapted [13, 14, 194, 195] (Table 1). When they changed from the census questions to the WG questions, countries such as Zambia and Malawi saw an increase in the estimated prevalence of disability [13, 116], suggesting a more reliable reflection of the number of people with disability in the country.

Table 1: Census questions on Disability Designed by UN Washington Group on Disability Statistics

Because of a physical, mental, or emotional health condition…
1. Do you have difficulty seeing even if wearing glasses?
2. Do you have difficulty hearing even if using hearing aid/s or are you deaf?
3. Do you have difficulty walking or climbing stairs?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Do you have difficulty communicating (for example, understanding or being understood by others)?
Question response categories: No difficulty, Some difficulty, A lot of difficulty, Unable to do

The WG Expanded Short Set of questions includes a question on upper body impairment ("Do you have difficulty raising a 2-litre jug of water from waist to eye level?") and questions to further test cognition in children ("Do you / Does [name] have difficulty learning new things?") and adults ("Do you have difficulty understanding and using information like following directions to get to a new place?").

The Washington Group did not include questions on pain, affect or fatigue in the Short and Expanded Short Set. For this, the Extended Set (Appendix I) was created that contains all 10 constructs and explores these in greater detail [196].

2.7.4 The WHODAS-2

The WHODAS-2 was used in the current study to assess the life domains in which most people with disabilities were experiencing activity limitations and participation restrictions.

The WHODAS-2, has its conceptual grounding in the ICF framework, and corresponds to the dimension of Activities and Participation [197]. According to Perenboom (2003), however, the questions related to Staying by Yourself and Time spent on Health Condition do not have any equivalence in the ICF [198]. The WHODAS-2 is an improvement on the WHODAS, and was developed to ensure cross-cultural adaptation, being tested for validity and reliability across numerous countries [199]. The development of the instrument was rigorous and is outlined in the WHO Bulletin [197]. The WHODAS-2 has been used to establish disability prevalence among the elderly in both local and international contexts [147, 148, 200, 201]. Reliability and validity have also been established across different cultures and health conditions [152, 197, 200, 202-210]. The WHODAS-2 is available in a 12-item and a 36-item version. It has been shown to have good concurrent validity with other instruments that measure similar disability constructs such as the SF-36, WHOQOL, London Handicap Scale and the Functional Independent Measure (FIM) [197].

2.7.5 WHOQOL-BREF

The WHOQOL-BREF was used in the current study to assess the subjective well-being among those who were identified as having a disability.

The WHOQOL-BREF is a generic quality of life instrument that measure people's perception of their position in life, in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns [211]. The WHO definition shows that the construct of QoL is subjective and is embedded in a cultural, social and environmental

context – thus highlighting the specific life areas in which an individual may experience barriers.

The WHOQOL-BREF is a 26-item version of the WHOQOL-100 that was developed through a multi-centre collaboration in 23 countries. The advantage of this approach is that it provides a fast-tracked multi-lingual instrument [212]. Although no African countries were included in the development of the WHOQOL-BREF, the instrument has been used across various settings in Africa [147, 213, 214]. It has shown very good reliability within these contexts, achieving a Cronbach`s alpha of > =0.7 [147, 213]. However, poor construct validity has also been reported in other studies [215-217]. The domain of Social Relationships has consistently shown poor alpha coefficients [212, 215], which could be attributed to the small number of questions in this domain. The WHOQOL-BREF has also demonstrated good discriminate validity [212, 218]. It has been widely used across health conditions [169, 219-223] and has been shown to have concurrent validity with other QoL instruments such as the SF-36 and EQ-5D [169, 224].

2.7.6 EQ-5D

The EQ-5D-3L was developed by the EuroQoL Group and is a standardised generic instrument for describing and valuing HRQoL. It consists of five descriptor domains namely mobility, self-care, usual activities, pain/discomfort and anxiety/depression, each with a three-point (no problem to severe) scale. In addition, a visual analogue scale (VAS) allows the respondent to indicate on a scale from 0 (worst health imaginable) to 100 (best health imaginable) how they judge their current health status. The advantage of the EQ-5D is that the VAS score can be used to record a person's perceived health status at a given time, and can be used to measure change over time [225]. Based on large-scale studies to generate valuations for the health states, a utility index has been developed which allows for the calculation of an index score for each health state. For example, the value of the health state described as No pain, No problems with self-care, Some problems with usual activities, Severe pain/discomfort and Severe anxiety/depression is 0.255, where 1.00 is full health. This index score summarises the descriptor domains and can be used as a cardinal value in statistical analysis. The EQ-5D index score can be used in cost-utility analysis to evaluate the impact of health care interventions [226, 227]. The VAS and the index score were used in the current study to assess the correlation between QoL and functional ability.

When used with other instruments, the EQ-5D has shown good concurrent validity [228, 229]. The EQ-5D has often been selected for its simplicity and brevity, and the SF-36 for its broader coverage of aspects related to HRQoL [230]. The EQ-5D has been validated for use in a South

African context, with good sematic equivalence obtained in the isiXhosa version of the instrument [231, 232] and was thus selected for the current study.

2.8 Conclusion

It is clear that the conceptualisation of disability has evolved with very little change on the ground to facilitate the inclusion of people with disabilities. Especially in low and middle-income countries and under-resourced communities, people with disabilities are at greater risk of developing further disability due to their higher risk of non-communicable diseases and their poor environments. Marginalised population groups in South Africa are at greater risk of disability in both rural and urban areas. Gender, ethnicity and age have an impact on the experience of disability.

The instruments chosen to explore disability in the current study are suitable for the context and have been widely used in similar contexts.

3 Methodology

3.1 Introduction

In order to determine the extent and impact of disability within poorly resourced areas in the Western Cape, two large-scale community-based surveys were undertaken in Oudtshoorn and the township of Nyanga in Cape Town. This chapter outlines the methodology used to collect data. The objectives of the survey were as stated in Chapter 1.

3.2 Study Design

A descriptive analytical cross-sectional study design was used, in which door-to-door household surveys were conducted in Nyanga and Oudtshoorn. Two-stage cluster sampling was employed as this is considered less resource-intensive than random sampling [233]. Despite the disadvantage of increasing the design effect, it allows collection of a large amount of data within a relatively short time. By sampling different clusters, the inference across the sample is improved [234]. Two-stage sampling was used, whereby a randomly selected group of informants was first identified, and then detailed information was gathered from those identified by the informants as having a disability. The person with disability was approached and asked to participate or be interviewed at a subsequent visit.

3.3 Sampling

3.3.1 Sample size

The sample size was calculated using Epi-Info Stat Calc, Version 6. As cluster sampling was used at the level of geographical area and household, a design effect of 1.3 was used. The design effect is a factor that reflects the effect on the precision of a survey estimate due to the difference between the sample design actually used to collect the data, and a simple random sample of respondents [234]. This effect was chosen based on a multi-stage sampling household survey in the UK (Health Survey for England 1994) that reported design effects ranging from 1.05 through to 1.57 for different risk behaviours and health conditions at the household level [235].

The district-based census of 2001 showed the combined population of the Nyanga district to be approximately 170,000, and that of the Oudtshoorn district to be 123,000. Assuming a population of 100,000 with an estimated prevalence of disability of 5.2% [236], a confidence interval of 0.6% (precision of 4.6 to 5.8%) and a 1.3 design effect, a sample of 3249 was required in each site. This would result in a 95% confidence level that the true proportion in the entire population would fall within the confidence interval calculated from the sample. Anticipating that the average household size consisted of 3.75 people [70], the final number of households to be visited was 866 in each area. In order to allow for non-responders, we identified 1000 households in each area.

3.3.2 Selection of Households

Households were identified through multi-stage selection to ensure that all socio-economic groupings were represented. Google aerial-view maps of the two areas were used to identify areas of informal, formal, flats (apartment blocks) and backyard dwellings. Geographical areas delimited by streets were marked off on a Google map based on their relative size, as judged by the number of streets per area. These areas were numbered and then a random sample of these areas was chosen using the Excel Random Number selection function. If an area was chosen twice, it was resampled. Within each geographic area or mini-cluster selected, four "corners" were identified from which the enumerators were required to start and then to move to the household one away to the left of the selected house. In other words, every second house within the cluster was visited.

3.3.2.1 Nyanga

It was possible to identify four dwelling types on the Google map. The number of clusters in each dwelling type was roughly based on the proportion of dwelling type as reported in the 2001 National Census (2) (Table 2).

Table 2: Sampling frame for Nyanga (based on 2001 Census [6, 9]

	Number	%	No. of units chosen
Formal dwellings	5483	45.2	480
Informal dwellings, including backyard and traditional dwellings	5323	41.1	480
Backyard dwellings	1284	9.9	53
Flat in block of flats	595	4.6	48
Other	252	1.9	
Total	12937	100	1061

Four of 21 clusters of formal dwellings (Figure 2) and four of 14 clusters of informal dwellings (Figure 3) were randomly chosen. In each, six streets were randomly chosen and 20 houses were visited in every street.

Figure 2: Google aerial map of Nyanga with 21 "clusters" of formal housing identified

Figure 3: Google aerial map of Nyanga with 13 "clusters" of informal housing identified

Five blocks of 64 flats were randomly selected and in each block, one floor was randomly chosen and eight flats were visited, starting from a random point on that floor. Five of 29 clusters of backyard dwellings were chosen. One area of the 21 formal housing areas was selected randomly from those that were not included in the formal housing sector. Five clusters were chosen and fifteen dwellings chosen in each. As the number of backyard dwellings was small, the enumerators were instructed to start at the designated corner and continue recruiting in every house that had a backyard structure until ten households were interviewed in each cluster.

3.3.2.2 Oudtshoorn

Fifteen clusters were identified from an aerial-view map, with approximately ten streets in each. Clusters that represented areas previously reserved for Whites only[3] were excluded from further sampling. Ten clusters remained, and from these, five were randomly selected for inclusion in the sample and 200 households visited in each.

In summary, cluster sampling was used in both geographical areas, with stratification for dwelling type in Nyanga. If for any reason respondents in the identified household could not be interviewed, a further visit at an alternative time was attempted before exclusion.

3.3.3 Selection of participants

Subjects of the surveys included all adults and children who were permanent residents in the identified household. The most senior member present at the time of the visit or the head of the household was asked to provide information on all the other members. Information was only gathered on members of the household that were older than 5 years, as the WG questions were not appropriate for children under five years of age [12].

All people with disabilities identified by the informants were followed up. The information of the person with disability was included in the general survey even if the person was not included in the disability-specific survey due to problems with making contact on follow-up. As

[3] The Group Areas Act was promulgated in 1957 and only abolished in 1991. This Act was used to assign different racial groups to specific residential and business areas – with the supreme effect of excluding "non-whites" from more developed areas. The areas designated to "non-whites" were in most cases far from the central business district, resulting in non-whites having to commute large distances from their homes to their places of work. (http://en.wikipedia.org/wiki/Group_Areas_Act)

most of the disability questionnaires had not been validated for children, only respondents aged 15 years or older were included in the sample of people with disabilities.

3.4 Instrumentation

Several standardised instruments were used to collect data. They are described in more detail in Section 2.7. If isiXhosa and Afrikaans versions of the standardised questionnaire were not available, they were produced by professional translators using a standard protocol involving forward and backward translation. The validity of the WHODAS-2 and the WHOQOL-BREF was examined post hoc. The questionnaires were completed either by the informants, the respondents identified as having a disability, or both.

3.4.1 Demographic details

Basic demographic details about the informants and household members were collected with a self-designed questionnaire (See appendix I). There were three sections concerned with demographic characteristics (e.g. age, education), social characteristics (e.g. household composition) and biomedical characteristics. A panel that included experts in the field of epidemiology examined the content validity: a public health specialist, an obstetrician and a physiotherapist who has run several community-based surveys. The instruments were tested during the piloting of the project for cultural appropriateness and clarity and amended as suggested by the field researchers. Respondents with disabilities were asked to describe their health condition and the underlying cause of their disability. These were written down by the field assistants and transcribed verbatim into the Excel data sheet.

3.4.2 Washington Short Set Questions

The Washington Group on Disability Statistics Short Set Questions [12] were used to identify persons with disability (See Section 2.7.3). The informants were asked to report on all household members using this questionnaire. In addition, the questionnaire was administered to people with disability who were subsequently interviewed.

3.4.3 Quality of life

This was examined using the EQ-5D and the WHOQOL-BREF as they are complementary. The EQ-5D monitors health-related quality of life (HRQoL) and the WHOQOL-BREF general quality of life. The EQ-5D generates a utility or index value that can be used in statistical analysis. The WHOQOL-BREF includes questions on participation and environmental factors, and better reflects the ICF constructs.

3.4.3.1 EQ-5D

The EQ-5D-3L instrument (See Section 2.7.6) was used to determine the HRQoL of informants and adults with disability. It was translated into Afrikaans and isiXhosa and both versions were approved by the EuroQoL Research Foundation (http://www.euroqol.org/). In addition, the isiXhosa version was validated in a similar setting to Nyanga in Cape Town (Khayalitsha) [231, 232]. The York Tariff was used to calculate the utility value of each health state [237]. Generally self-report was used, but in the cases where the disabled person themselves were unable to respond, proxy report was used. It has not been validated for younger children and these were excluded.

3.4.3.2 WHOQOL-BREF

The WHOQOL-BREF was used to document the QoL of the informants and adults with disabilities. Translations were undertaken and the two language versions were used in the study. As it has only been validated for use in adults, children were excluded from completing this questionnaire. The validity of this instrument was examined post hoc (Chapter 10).

3.4.4 Functional Ability – WHODAS-2

The Afrikaans or isiXhosa version of the WHODAS-2 (See Section 2.7.4) was administered to adults with disabilities to determine the functional impact of their disability. Similar to the WHOQOL-BREF, it has only been validated for use in adults and thus children were excluded from completing it. The validity of this instrument was examined post hoc.

3.5 Procedure

Ethical approval for the study was obtained from the Human Research Ethics Committee at the University of Cape Town (HREC 098/2012), and permission for the survey was obtained from the Western Cape Department of Health.

3.5.1 Fieldworkers

A list of home-based care organisations in the Nyanga district was obtained from the Director of Community Based Services at the Western Cape Department of Health. The organisations were contacted and invited to assist as data collectors. Only one organisation accepted. In Oudtshoorn, the fieldworkers used during the recent national census were recruited as data collectors. There were ten enumerators per area and they were trained over a two-day period in administering the questionnaires.

3.5.2 Training and piloting

A cluster in each of the sites, not selected in the sampling strategy, was randomly selected for the pilot study. The main aims of the pilot study were to test the feasibility of the household selection and the face and content validity of the questionnaires. In both sites, the pilot study was conducted immediately after the training session. Four "corners" were identified in each cluster, and the street on each corner was identified as the starting point. The enumerator visited every second house to the left of the first house, until they had interviewed five households. Only three refusals were encountered. The respondents had no difficulties in responding to the questionnaires, and the average time for completing the household questionnaire was 20 minutes. Only three households had a person identified with a disability, and the time taken for completion varied according to the severity of the disability, the mean time being 45 minutes; one was completed via proxy. There were no procedural difficulties detected. Within the WHODAS-2, however, some of the enumerators found it difficult to ask the question related to sex life. They felt embarrassed to ask those who were older than they were about their sex life. A further workshop was held on how to ask the question without it being personal. Enumerators were instructed to read the question as it was on the questionnaire, or to allow the respondent to read the question him/herself.

3.5.3 Data collection

Data collection was started in April 2011 and was completed by January 2012. A supervisor was appointed to oversee the data collection and deal with any logistical problems that may have arisen. This was also used as a quality assurance mechanism. Each enumerator was given a map of the street names that they had to visit, and the corner from which to start was identified. Upon visiting a household, the enumerators asked to see the head of the household or the most senior member of that household present at the time. Informed consent was obtained from this person after the purpose of the research and the procedure had been explained. Information was obtained on all members of the household via this respondent. If the respondent reported that there was a person with a disability in the household, then the person with disability was asked to participate by completing a questionnaire measuring the impact of disability. If the person with a disability was not present, an appointment was made and the home was revisited.

Data collection in Oudtshoorn was started after the data collection period in Nyanga. Each enumerator was expected to complete at least five questionnaires per day over 20 days. Enumerators were compensated per questionnaire completed.

3.5.4 Ethical Considerations

Permission to conduct the survey was obtained from the Western Cape Department of Health, and ethical approval was obtained from the Human Research Ethics Committee at the University of Cape Town (HREC Ref 098 /2012). The purpose of the study was explained to all eligible participants and written information sheets were provided (II). Written informed consent was obtained from all adult informants. In the case of minors or disabled persons who were not able to give legal consent, written assent was obtained from the parent(s)/legal guardian (Appendix III). Participants were informed that participation in this study was voluntary and that refusal to participate or withdrawal would have no negative influence on the household or any member of the household. Participants were also informed that they would not be given any financial reward for their participation. Participants were informed that all data obtained would be kept confidential and that at no time would the identity of the people or households be revealed in any reports generated from the study.

Whenever possible, but depending of the circumstances of the household, adult informants were interviewed in a quiet setting and on their own. Minors (under the age of 18 years) were interviewed in the presence of their parent(s) or guardian(s). In Nyanga, the enumerators were home-based carers, and where people were identified requiring medical or social intervention, they were referred to the nurse co-ordinator of their organisation. In Oudtshoorn, persons were informed of services that they could utilise within the area.

The study was performed in accordance with the principles of the Declaration of Helsinki [29].

3.6 Data Management and Analysis

Raw data was captured manually on paper questionnaires and then entered into an Excel spreadsheet. Double entries of a random sample of questionnaires were done to ensure that the data were accurately captured. Epi Info StatCalc was used to determine sample size. The Excel spreadsheets were exported into Statistica version 11 for analysis. SPSS Version 22 was used to examine the internal consistency of the instruments. The Odds Ratios were calculated using MedCalc (www.medcalc.org). The prevalence estimates were based on observed frequencies of disability. Prevalence for disability was derived from those scoring some difficulty (2), a lot of difficulty (3) and unable to do (4), based on the Washington Group Screening Questions. For the purpose of this study a person presenting with some difficulty in any of the domains of the Washington Group questions will be identified as a person with a

disability. For the purpose of establishing disability prevalence, the most severe of the disabilities were noted. However, when establishing frequency of impairments and functional limitations all difficulties were counted .

HYLL (Healthy years of life lost) were calculated as follows: the EQ-5D utility score, which represents the value of one year lived in a particular health state, was calculated for each condition[4]. The value of the health condition using the EQ-5D weights ranges from a negative value (if the condition is very severe) to 1 (full health). Therefore this value was subtracted from 1 to calculate the loss of healthy life or Healthy Years of Life Lost (HYLL) due to disability. The years since the onset of the condition were then multiplied with this score to calculate the number of HYLL and these were summed to determine the total burden due to disability attributed to each condition.

The WHOQOL-BREF algorithm was used to compute domain scores [238]. Similarly, the WHODAS algorithm was used to calculate the mean scores in the six domains [104]. Rather than simply summing the responses, the scores are weighted on values based on Item Response Theory [104, 238]. Where there were missing data, values were calculated excluding these items. The WHODAS algorithm was also used to calculate the mean score of the scale in

[4] An example of calculating the utility weight for a health state : Calculating EQ-5D state scores - a worked example using the York Tariff developed by Dolan (1997):

EuroQoL dimension	Level 2	Level 3
Mobility	0.069	0.314
Self-care	0.104	0.214
Usual activity	0.036	0.094
Pain / discomfort	0.123	0.386
Anxiety / depression	0.071	0.236

Constant = 0.081 N3 = 0.269

The arithmetic needed to recover the estimated value for any health state from this table of decrements is given by the following example:

Taking health state 1 1 2 2 3
Full health (1 1 1 1 1) = 1.0
Constant term (for any dysfunctional state)(subtract 0.081)
Mobility.. level 1(subtract 0)
Self-care.. level 1(subtract 0)
Usual activity.. level 2(subtract 0.036)
Pain / discomfort.. level 2(subtract 0.123)
Anxiety / depression.. level 3(subtract 0.236)

Level 3 occurs within at least 1 dimension(subtract N3 parameter 0.269)

Hence the estimated value for state 1 1 2 3 3 is given by
1.0 - 0.081 - 0.036 - 0.123 - 0.236 - 0.269 = 0.255

total. This allowed for the use of the scores as interval data and, as the numbers were large, the central limits theory held. As internal consistency was generally found to be excellent (Cronbach's $\alpha \geq 0.9$) (See Chapter 11 for analysis of the psychometric properties of the instruments) and the number of respondents was over 200[5], parametric statistics were used to analyse the results of these instruments. The causes of disability were recoded into the Burden of Disease categories, which are communicable diseases, non- communicable diseases, maternal and child health, intentional trauma, unintentional trauma, musculoskeletal, mental health and other. They are presented using frequency tables.

The psychometric properties of the WHODAS-2 and the WHOQOL-BREF were examined using Cronbach's alpha and item-total correlations to establish the reliability and internal consistency of the instruments and the constituent domains. Construct validity, specifically convergent and divergent validity were examined using confirmatory factor analysis, and concurrent validity was tested using Pearson's correlations. In each case, a p value of <0.05 was considered to be statistically significant.The details of the statistical analysis are given in Table 3.

Table 3: Details of statistical analysis undertaken

Research question	Analysis	Presented as
Were the demographic characteristics similar between the following groups? -respondents in the two sites - those who screened positive for disability and the entire sample -those screening positive for disability and those eventually interviewed.	Pearson Chi Square (Chi Sq) for categorical data such as gender and number of refusals Mann Whitney U to compare ordinal data such as income levels. t-tests to compare numeric data such as ages, household size. Calculated with separate variances if the F statistic was significant. Note that the age distribution was noticeably skewed in Oudtshoorn and the Mann Whitney U was used to compare ages across the sites in this case.	2x2 tables Z statistic, histograms T value, histograms
What is the prevalence of disability in under resourced areas in the Western Cape?	Numerator = with problems identified by WG questions. Denominator=number reported on by the informants. Analysed by site and overall.	Percentage plus 95% confidence intervals (CI) Line plots
Is there a difference in the prevalence and pattern of disability between urban and semi-rural areas?	The mean ages of each severity level were compared with a factorial ANOVA	F statistic Line graphs

[5] The central limit theorem implies that the average will follow approximately a normal distribution, as the sample size increases (239. Aberson CL, Berger DE, Healy MR, Kyle DJ, Romero VL: **Evaluation of an interactive tutorial for teaching the central limit theorem**. *Teaching of Psychology* 2000, **27**(4):289-291.) The minimum sample size is usually taken as 30. Even with extreme deviations from normality, a sample size of approximately 80 is usually enough to run a *t*-test. (Salnani, K Dealing with non-normal data. Vol. 4, 1001-1005, December 2012 http://dx.doi.org/10.1016/j.pmrj.2012.10.01

What are most the common types of disability in these areas?	Frequency tables	
What health conditions are related to disability and does the age of onset differ for the conditions? Do the conditions differ across the two areas?	The odds ratios (ORs) of having the condition and living in Oudtshoorn were calculated. A one-way ANOVA and a post hoc Tukey test were used to establish if there was a difference in age of onset and current age for each condition	ORs, 95% CIs and significance level
What is the "burden" due to disability for the most common underlying causes of health condition? Does it differ between the sites?	The HYLL was calculated and summed for each condition and each site. A t-test was done to compare the total HYLL across sites.	HYLL per condition. Total HYLL per site. Line graph comparing condition and site. t-statistic
What is the impact of disability on function, in other words what are the most common functional limitations? What is the relationship between the domains and age? Does the type of disability predict the WHODAS-2 domain scores?	Frequency per site plus 95% CIs. The WHODAS-2 score was calculated using the algorithm based on item response theory and used as a numeric measure. A repeated measures ANOVA and post-hoc Tukey were used to compare the mean scores of the different domains of the WHODAS-2. Spearman's correlation was used to establish if there was a correlation between the domain scores, the age of the respondents and the WHODAS-2 score. The mean scores of each domain were compared using the t-test. Multiple regression analysis was used to identify which variables predicted the WHODAS-2 scores. Dummy variables were created for demographic variables and all variables were entered into the equation simultaneously. Outliers (residual scores more than 3 SDs from the mean) were identified and their scores removed.	Histograms F statistic Line plots Spearman's r t-values Regression coefficients and adjusted r^2 scores Spearman's r Scatterplot.
What is the impact of disability on health-related quality of life (HRQoL) and does this differ between the two areas? What demographic factors and which type of disability predict the scores on the different domains?	Repeated measures ANOVA and post hoc Tukey test were used to compare the domain scores. t-tests were used to compare each domain and the total score across the two sites for both the WHOQOL-BREF and the EQ-5D-3L. Multiple regression analysis was used to identify which variables predicted the WHODAS-2 scores. Dummy variables were created for demographic variables and all variables were entered into the equation simultaneously. Outliers (residual scores more than 3 SDs from the mean) were identified and their scores removed. The correlation between the EQ-5D VAS and domain scores was established	F values t-statistic Regression coefficients and adjusted r^2 scores Spearman's r Scatterplot.
What environmental barriers are experienced? Is there a difference in disability profile between those who access services and those who do not? Do the two areas differ?	Chi-sq to compare the number of people requiring services and receiving services across the two sites and across age bands t-tests to comparing the functional levels of those accessing services and those not	Histograms Chi-sq t-test Line graphs
Validation of the isiXhosa and Afrikaans versions of the WHOQOL-	Tests of internal consistency including calculation of alpha if each item was removed. Cronbach's alpha was	Cronbach's alpha

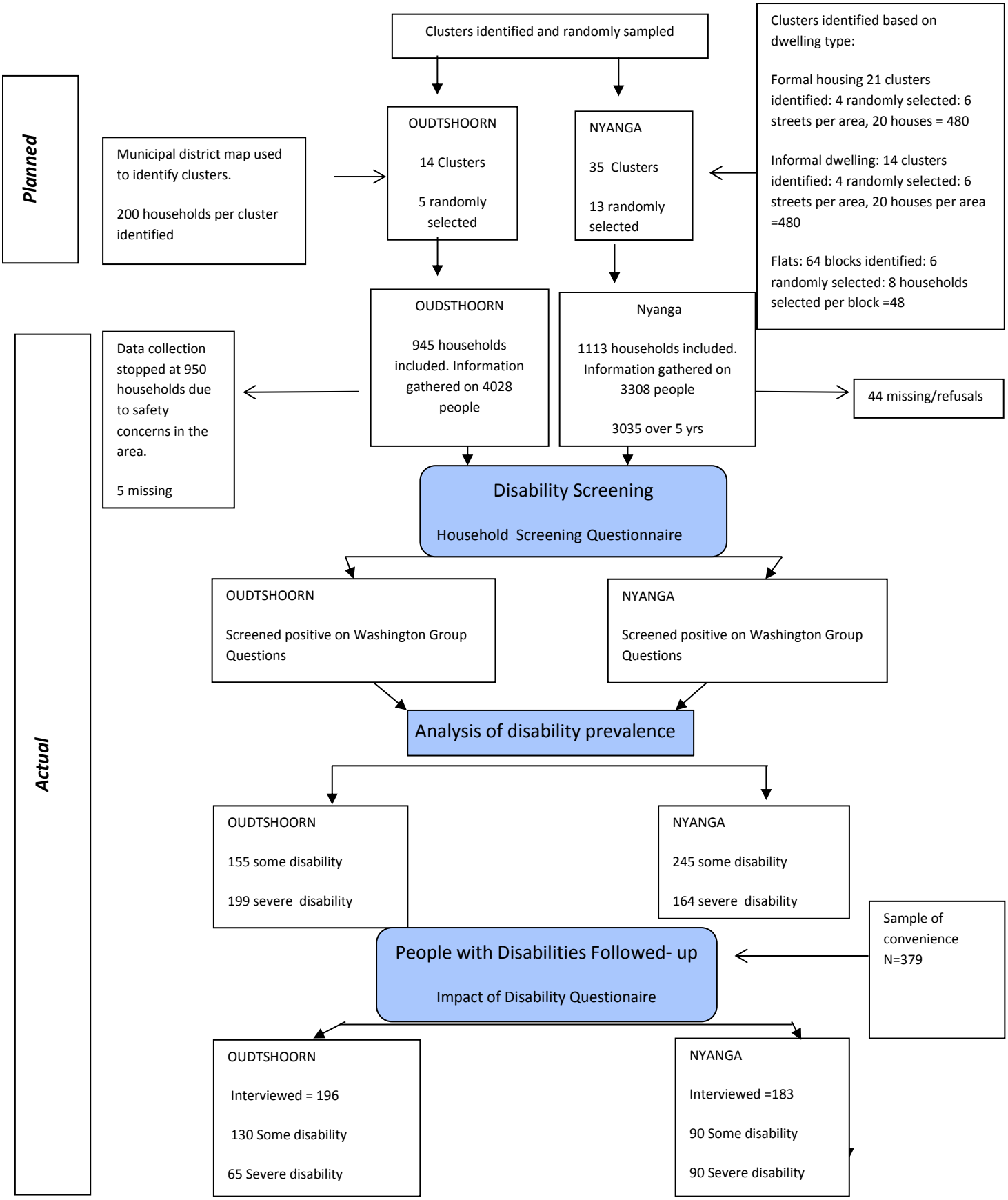
BREF and the WHODAS-2	interpreted as described below[6] Confirmatory factor analysis to test the validity of the domains as identified by the developers of the instruments. Six factors were stipulated for the WHODAS-2 and four for the WHOQOL-BREF Correlations between the EQ-5D VAS and Utility score and the total of the WHOQOL-BREF and WHODAS-2 scores. Regression analysis to establish relative contribution of the WHOQOL-BREF and WHODAS-2 to the utility and VAS scores of the EQ-5D.	Factors and loadings of each item on each factor. Correlation matrix Scatterplots Coefficients and adjusted r^2.

In each case, a p value of <0.05 was considered to be statistically significant.

[6] A commonly accepted[rule of thumb for describing internal consistency using Cronbach's alpha is as follows, however, a greater number of items in the test can artificially inflate the value of alpha[8] and a sample with a narrow range can deflate it, so this rule of thumb should be used with caution:

Cronbach's alpha	**Internal consistency**
$\alpha \geq 0.9$	Excellent (High-Stakes testing)
$0.7 \leq \alpha < 0.9$	Good (Low-Stakes testing)
$0.6 \leq \alpha < 0.7$	Acceptable
$0.5 \leq \alpha < 0.6$	Poor
$\alpha < 0.5$	Unacceptable

Figure 4: Diagrammatic representation of the study



4 Disability Prevalence: Results and discussion

4.1 Introduction

Disability prevalence refers to the number of people who were identified by the informants as presenting with disability at the time of interview. Disability is defined as reporting some or severe problems in any one of the WG domains. This chapter aims to address the following objectives:

- To establish whether the prevalence and severity of disability of persons living in under- resourced communities as measured using the Washington Group Screening Questions was similar to that described in the national census and other household surveys
- To determine if there was a difference between the two geographical areas with regard to pattern and prevalence of disability.

4.2 Demographic details of the sample

Altogether 2107 households were approached in the two areas, Nyanga and Oudtshoorn (Table 4). More households were visited in Nyanga than Oudtshoorn, and there was a significant association between refusals/missing data in that there were more in Nyanga ($p<0.001$). Data were recorded on 7336 individuals, of which 699 were aged 5 years or less and were excluded (426 in Oudtshoorn and 273 in Nyanga). Information was obtained on 3602 individuals in 940 households in Oudtshoorn, and 3035 individuals in 1113 households in Nyanga. The mean age of the entire sample was 32.8 (SD 18.0) years and there was no significant difference in the age between the two areas (Figure 5).

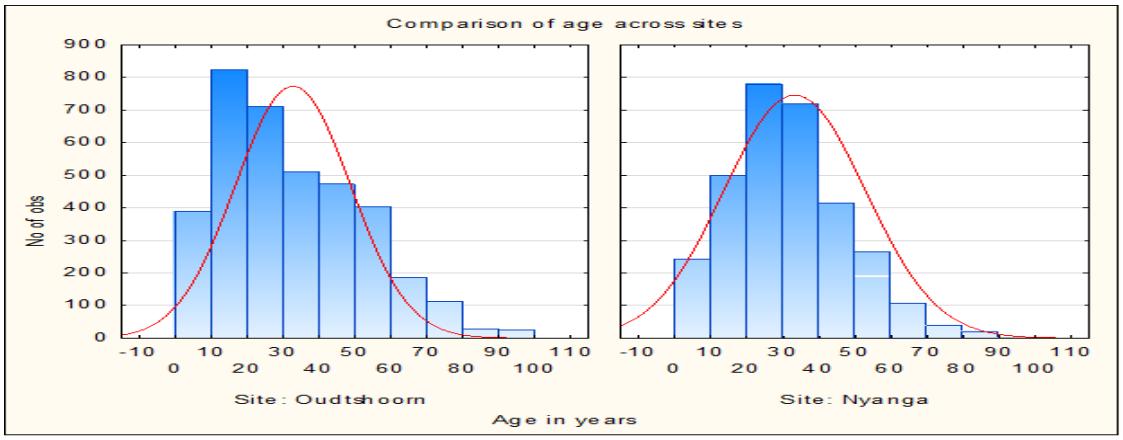


Figure 5: Age distribution of the sample across the two sites (Oudtshoorn N=3665; Nyanga N=3087)

The mean age of the informants was 45.8 years (SD 13.9) and the Oudtshoorn informants were significantly older than those in Nyanga (p<0.001). In Oudtshoorn, there were fewer males among the informants (49.3%) compared to in Nyanga (52%, p=0.033). The average household size was greater in Oudtshoorn (Table 4).

Table 4: Demographic details of surveyed sample

	Oudtshoorn	Nyanga	Total	p value Oudtshoorn vs Nyanga
Households approached	950	1157	2107	***Chi-sq=24.66, p<0.001***
Households included	945	1113	2058	
Refusals/missing	5	44	49	
Persons on whom data were collected (N)	4028	3308	7336	
Number excluding children under 5 years	3602	3035	6637	
Care dependency ratio (Children+Elderly)/Adults[7]	0.47	0.25		
Entire sample (excluding under 5s): Mean age (SD), Range	33.0 (19.6) 6-98 years N=3602	32.5(15.9) 6-93 years N=3035	32.8 (18.0) 6-98 years N=6637	t=1.11 p=0.267

[7] **Definition of Dependency Ratio:** The dependency ratio measures the % of dependent people (not of working age) / number of people of working age (economically active)
Dependency Ratio =
(Number of Children (0-15) + Number of Pensioners (> 65))/Number of working age 16-65
http://www.economicshelp.org/blog/glossary/dependency-ratio/ Accessed October 2014

	Oudtshoorn	Nyanga	Total	p value Oudtshoorn vs Nyanga
Entire sample (excluding under 5 years): Males	46.2% N=1600	46.2% N=1397	45.6% N=2997	Chi Sq=0.059 p=0.808
Informants: Mean age (SD), Range	50.1 (14.6) 13-98 N=939 Missing = 6	42.9 (12.6) 19-93 yrs N=1109 Missing = 4	45.8 (13.9) 18-93, N=2048 Missing = 10	*t=-12.02, p<.001 (estimated with separate variances)*
Informants: Males %	49.3% N=443 Missing=23	52.8% N=587 Missing =1	51% N=1030 Missing 24	***Chi Sq=4.53*** ***p=0.033***
Average household size (including young children)	4.3	3.0	3.6	
% employed between 15 and 65 years	28.0% of total N=2623	49.9% of total N=2559	38.8% of total N=5182	***Chi Sq=188.8*** ***P<0.001***
Income per month Median category (range)	R1000-2999 (<1000 to >13000) N=720 Missing=225	R3000-4999 (<1000 to > 13000) N=894 Missing=263	R1000-2999 (<1000 to > 13000) N=1614 Missing=488	***Adjusted Z=5.22, p<0.001***

The percentage of unemployment was significantly higher in Oudtshoorn with 38.8% of the total sample reporting some form of employment. The total income per month was significantly less for individuals living in Oudtshoorn but there were a large number of missing responses to the Income question in both sites. The median income category of the total sample was R1000-2999, and Oudtshoorn respondents reporting significantly less income than Nyanga respondents (Figure 6).

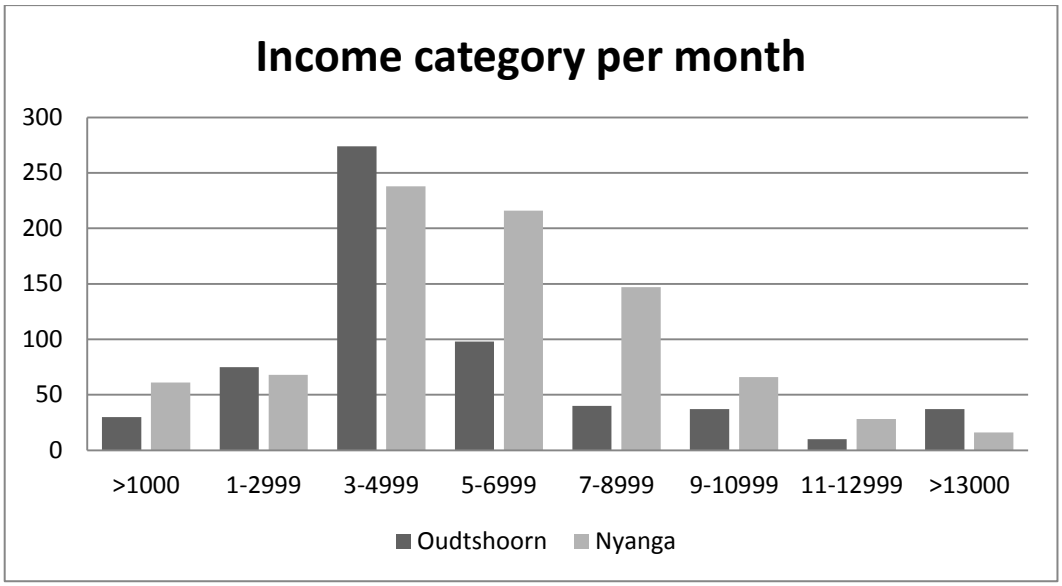


Figure 6: Income categories per month (Oudtshoorn N=720; missing=225, Nyanga N=894; missing=263)

4.3 Disability Prevalence

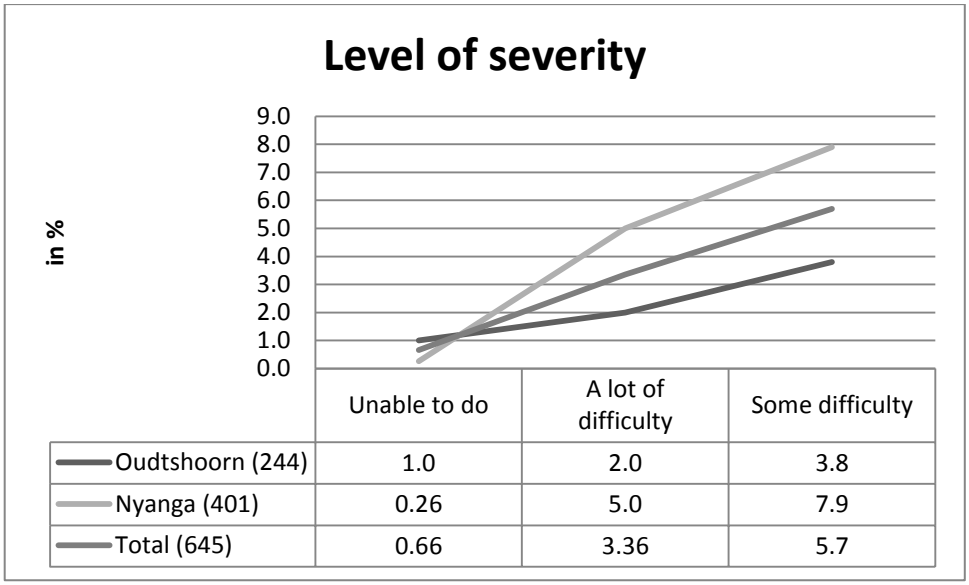
In all, 645 individuals screened positive for having difficulty in any one of the domains, which gave a prevalence of 9.7% (CI 9.0-10.4%). A significantly smaller proportion of respondents were identified as having a disability in Oudtshoorn (244, 6.8%, CI 5.9-7.6%) compared to Nyanga (401, 13.1%, CI 12.0-14.3%; Chi-sq=77.8, p<0.001) (Table 5).

Table 5: Severity of disability in the two sites (Oudtshoorn N=4028, Nyanga N=3308)

Site	No difficulty	Some difficulty	A Lot of difficulty	Unable to do	Number with any disability	Number
Oudtshoorn	3358	137	71	36	244	3602
%	93.2%	3.8%	2.0%	1.0%	6.8%	
95% CI	92.3-94.0	3.2-4.5	1.6-2.5	0.07-1.4	6.0-7.8	
Nyanga	2634	241	152	8	401	3035
%	86.8%	7.9%	5.0%	0.3%	13.2%	
95% CI	85.5-88.0	7.0-9.0	4.2-5.9	0.11-0.56	12.0-14.3	
Totals	5992	378	223	44	645	6637
%	90.3%	5.7%	3.4%	0.7%	9.7%	
95% CI	89.5-91.0	5.2-6.3	2.9-3.8	0.60-0.7	9.7-9.8	

Note that the CI have been rounded down to one decimal place.

The overall rate of “Severe” and “Unable to do” was 4.0% (CI 3.5-4.5) (Figure 7). The 95% CI for the percentage with disability increased with decreasing sample size from 1% in the total sample to 1.8% in Oudtshoorn and 2.3% in Nyanga. To achieve a 99% level of confidence in these estimates, the total sample needed to be 3174, with the Oudtshoorn sample being 2721 and the Nyanga sample 1323. All groups surpassed these numbers and the confidence levels of these estimates were thus 99%.



	Unable to do	A lot of difficulty	Some difficulty
Oudtshoorn (244)	1.0	2.0	3.8
Nyanga (401)	0.26	5.0	7.9
Total (645)	0.66	3.36	5.7

Figure 7: Disability prevalence by severity across the two site (Oudtshoorn N=3665, Nyanga N=3087)

Level of severity was significantly associated with site, with a larger proportion of those with disability reported as being “Unable to do” in Oudtshoorn (p<.001; Table 6).

Table 6: Comparison of levels of severity across sites (Oudtshoorn N=244, Nyanga N=401)

	Some problems	Severe Problems	Unable to do	Row Totals
Oudtshoorn	137	71	36	244
Row %	56.1%	29.1%	14.8%	
Nyanga	241	152	8	401
Row %	60.1%	37.9%	2.0%	
Totals	378	223	44	645

Chi-sq. =40.01, p<0.001

4.4 Demographics of people with disability compared with the surveyed group

There were more women than men amongst those who screened positive for disability. This group was also older, fewer were employed and the mean ranking of their income categories was lower (Table 7).

Table 7: Demographics of those who screened positive for disability compared to the overall survey sample

	Surveyed N=5992	**Disability N=645**	Test statistics
Male gender	2744 (46.8%)	253 (39.8%)	***Chi-sq=11.4 p=0.001***
Mean age (SD)	31.6 (16.8)	48.4 (19.2)	***t value =-21.29, p<.001 (Sep variances)***
Employed Age group>15	1926 (44.0%) (N=4381)	105 (19.5%) (N=539)	***Chi-sq=118.9 P<.001***
Median income category per month, range	R1000-2999 0->R13000	R1000-2999 0->R13000	***Z adjusted 6.18, p<.001***

4.5 Comparison in those screening positive for disability between the two sites

The mean age of those reported to have disability was 50.5 years (SD 20.4) in Oudtshoorn, which was approximately three years older than the Nyanga sample at 47.1 years (SD 18.4)(t-value -2.138, df=643, p=0.033) (Figure 8 and Table 8).

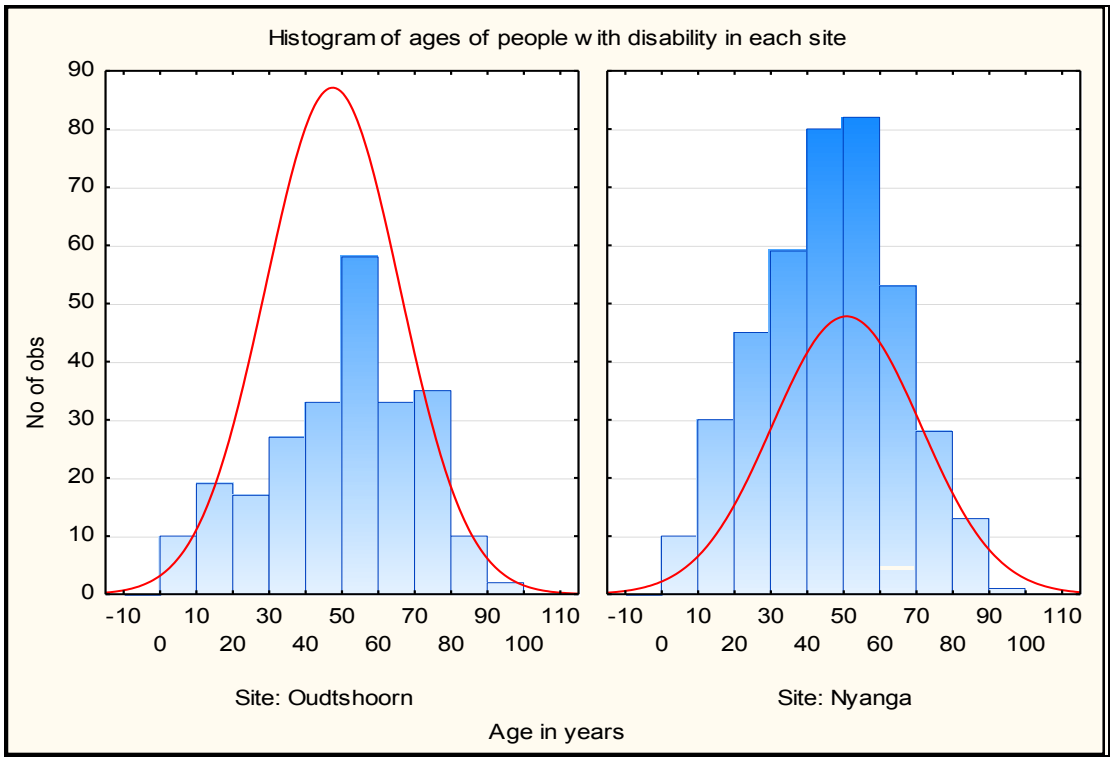


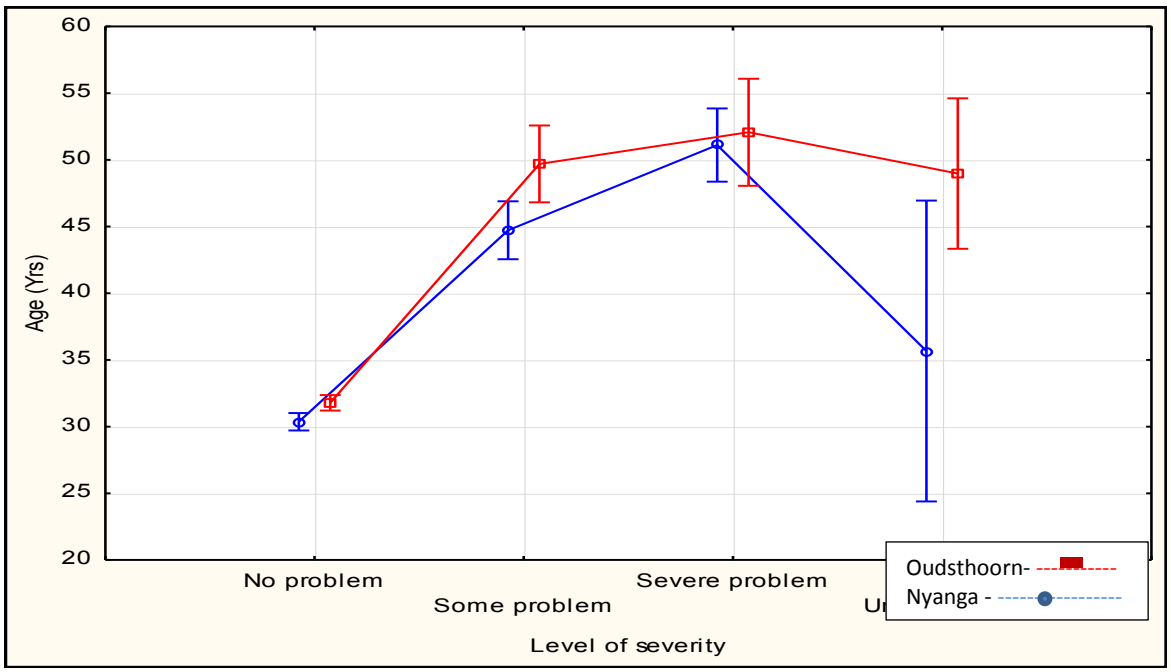
Figure 8: Ages of people with disability in the two sites (Oudtshoorn N=401, Nyanga N=244)

Table 8: Age distribution in the two areas (N=645)

	Youth (6-14 yrs)	Adult (15-59 yrs)	Elderly (60+ yrs)	Row Totals
Oudtshoorn	14	169	61	244
Row %	5.7%	69.3%	25.0%	
Nyanga	17	324	60	401
Row %	4.2%	80.8%	15.0%	
Totals	31	493	121	645

Chi-sq. 11.49 p=0.003

There was no difference between sites in the mean age of people with different levels of severity of disability (F(3, 6744)=2.30, p=0.075) (Figure 9).



Bars denote 95%CI. F(3, 6744)=2.30, p=0.075. Note that the CIs of the "Unable to do" in Nyanga are very large, reflecting the small sample size.

Figure 9: Mean ages of those with different levels of severity across the site (Oudtshoorn N=3602, Nyanga N=3035).

People with disability in Oudtshoorn were less likely to be employed, had lower income and were older than those in Nyanga (Table 9).

Table 9: Demographics of people screening positive for disability

	Oudtshoorn N=244	**Nyanga N=401**	**Total N=645**	Test statistics
Male gender	95 (40.3%)	158 (39.6%)	47.0%	Chi-sq.=0.027 p=0.871
Mean age (SD), Range	50.5 (20.4) 6-91	47.1 (18.4) 6-93	41.1 0-93	***t value =2.14, p=0.032***

Employed Age group>15	29 (16.2%) (N=179)	76 (20.4%) (N=372)	105 (19.0%) (N=552)	Chi-sq.=1.368 p=0.242
Median Income category per month, Range	R1000-2999 0->R13000	R3000-4999 0->R13000	R1000-2999 0->R13000	***Z adjusted 2.38, p=0.017***

4.6 Summary of findings

Fewer households were visited in Oudtshoorn but there were fewer refusals and a larger household size, which resulted in a larger sample. The Oudtshoorn sample had a larger group of children 5 years or younger, who were subsequently excluded. There was no difference in the mean sample age in the two areas. The sample included mostly females in both areas. Unemployment was higher in Oudtshoorn, and the monthly household income was less than that of Nyanga.

The overall prevalence of disability was 9.7% (CI 9.0-10.4) with 4.1% in the "Severe" and "Unable to do" categories combined. Those identified with disability were more likely than the general sample to be older (mean age 48.4 years) and to be women, were less likely to be employed and their monthly income was lower.

The prevalence of disability was lower in Oudtshoorn (6.8%, CI 5.9-7.6) than in Nyanga (13.2%, 12.0-14.3), but Oudtshoorn had a greater proportion reporting "Unable to do" (14.8% of people screening positive for disability, compared to 2.0%). Those with disability in Oudtshoorn were about three years older than in Nyanga and their median income was lower.

4.7 Discussion

A formidable gap has been reported to exist between the needs of people with disabilities in resource-constrained settings and the services available to them [1]. The unavailability, inaccessibility and ignorance of services, combined with other socio-demographic variables, are some of the factors contributing to this gap. It is further compounded by under-reporting on the number of people with disability and the severity of impairment. These are all factors that impede a co-ordinated plan for service delivery, especially in resource-constrained settings where services are mostly fragmented.

The most important findings of the study with regard to prevalence were that the prevalence rates were much higher than that reported by the General Health Surveys and National Census and not only were there differences between the two sites in prevalence of disability, the patterns differed with regard to severity and socio-demographic variables (ages and income of those with disabilities). Oudtshoorn had significantly lower disability prevalence, but the proportion of those who were reported as being "Unable to do" was higher. Those with a disability were also older in Oudtshoorn.

4.7.1 Discussion of sample

The findings of this study provide a quantitative profile (prevalence and demography) of people with disabilities in two under-resourced areas. Although the total sample size was not achieved in Oudtshoorn (i.e. visiting 1000 households), the method of sample selection resulted in respondents who were representative of their respective districts and the Western Cape i.e. there were more women than men, and the mean age of the study sample is comparable to that of the 2011 Census [31]. The smaller than anticipated sample size achieved after visiting more than 1000 households might be due to the unexpectedly small household size in Nyanga, and the larger size in Oudtshoorn. Satisfactory power was achieved (99% confidence level) however, as shown by post hoc analysis.

The areas under study could be considered poorly resourced or impoverished, since the approximate average annual household income recorded in the two sites, R36,000 ($3600), is much lower than the average household income recorded for the Western Cape (R143,461) in the 2011 Census. Oudtshoorn has been reported to have an average household income of R90,844, which was the second lowest for the Eden District [69]. The study sample appears to come from the poorer strata of the areas selected, recording a much lower monthly household income. As those in informal housing were oversampled (see Limitations of the study Section 4.8), this was not surprising.

The results are therefore of particular relevance to the most deprived section of the population and are not intended to be representative of the general South African population.

4.7.2 Prevalence rates

4.7.2.1 Overall prevalence

The first objective was to compare the prevalence and severity rates with the National Census and other surveys. The methodology of the 2009 General Household Survey (GHS) is the most

comparable to the current study, where children under the 5 years old were excluded. From 2009 to 2011 the GSH reported national rates of disability ranging from 5.1-6.3% and rates for the Western Cape ranging from 4-5%. Both of these figures fall considerably below and outside the confidence intervals of the current study (9.7%; CI 9-10.4), as do the rates based on the National Census (Figure 10).

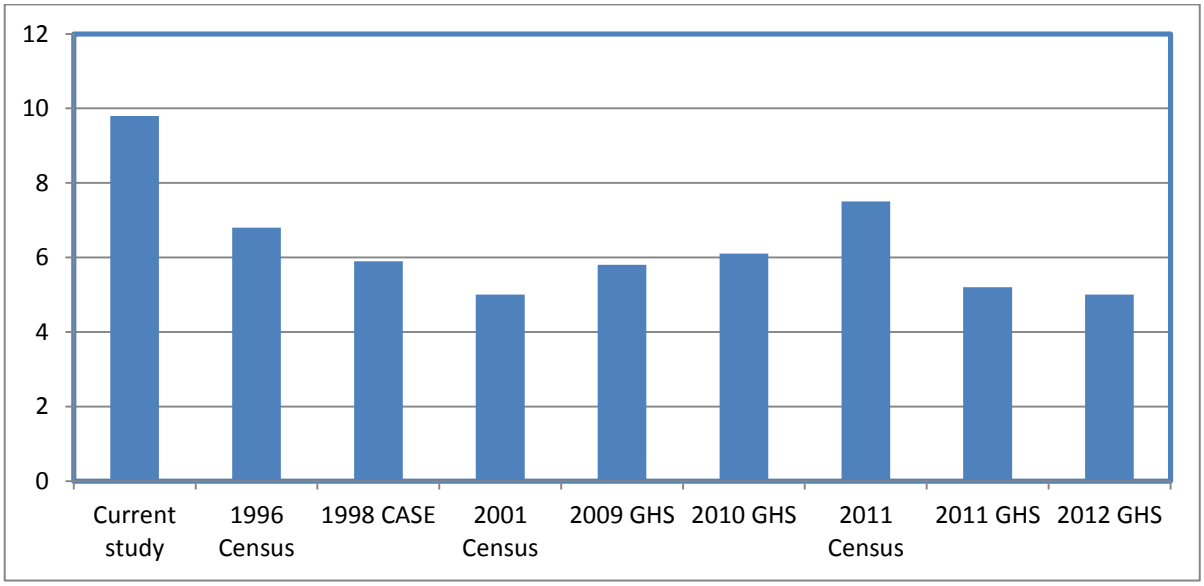


Figure 10: Comparison of overall rates of disability with other South African studies

It is remarkable that, despite the changes in methodology, the prevalence rate of disability in South Africa has not changed markedly over the past twenty years. The 1996 and 2001 disability censuses were based on a dichotomous response. The 1996 Census questions were posed in the medical model, "Does the person have a serious sight, hearing, physical or mental disability? If yes, circle all applicable disabilities for the person" [177]. Results computed from the 1996 Census micro-data estimated disability prevalence at 6.7% [32]. The 2001 disability census used the framework of the 1980 WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH), predecessor to the ICF, which defined disability as a physical or mental handicap which had lasted for six months or more, or is expected to last at least six months, and prevented the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities [5]. The question during the 2001 Census was changed to "Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? Mark any that apply: None, Sight, Hearing, Communication, Physical, Intellectual, Emotional (Yes/No response options)" which yielded a disability prevalence rate of 5% [33]. The 2011 Census (using the ICF

framework) and the WG questions (relating to difficulties with functioning due to health condition) yielded a disability prevalence rate of 7.5% [62].

The lack of variation in the disability prevalence reported by the five yearly censuses could be due to differences in the understanding of disability across government departments in South Africa. The 1998 Employment Equity Act No. 55 explains disability in terms of the ability of the person to be gainfully employed, whereas the 2004 Social Assistance Act No. 13 describes a disabled person by their ability to provide for themselves: “owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance”. The 1962 Income Tax Act No. 58 provides a more comprehensive definition of disability as “a moderate to severe limitation of a person`s ability to function or perform daily activities as a result of a physical, sensory, communication, intellectual or mental impairment, if the limitation has lasted or has a prognosis of lasting more than one year; and is diagnosed by a duly registered medical practitioner”. These qualifications imposed on the definitions could limit the self- identification of disability, especially among those with mild impairments. The higher prevalence obtained in 1996 could be attributed to the HIV pandemic and the unavailability of antiretroviral therapy, leaving many disabled due to the comorbidities associated with the disease. This assumption is made based on the high age-standardised mortality rate recorded in 1997, and the subsequent drop in mortality following the roll-out of antiretroviral therapy in 2005 [240].

In contrast, the overall disability prevalence in this study was found to be less than international estimates and those based on local surveys (Figure 11). The World Health Survey estimated a prevalence of 20%, the Global Burden of Disease study estimated 18% of the world’s population had some disability [82] [106], and a study in Zambia in 2006, estimated 20% [92]. The study conducted in a rural area in South Africa by Schneider et al reported a very high estimate of 32.5% [9].

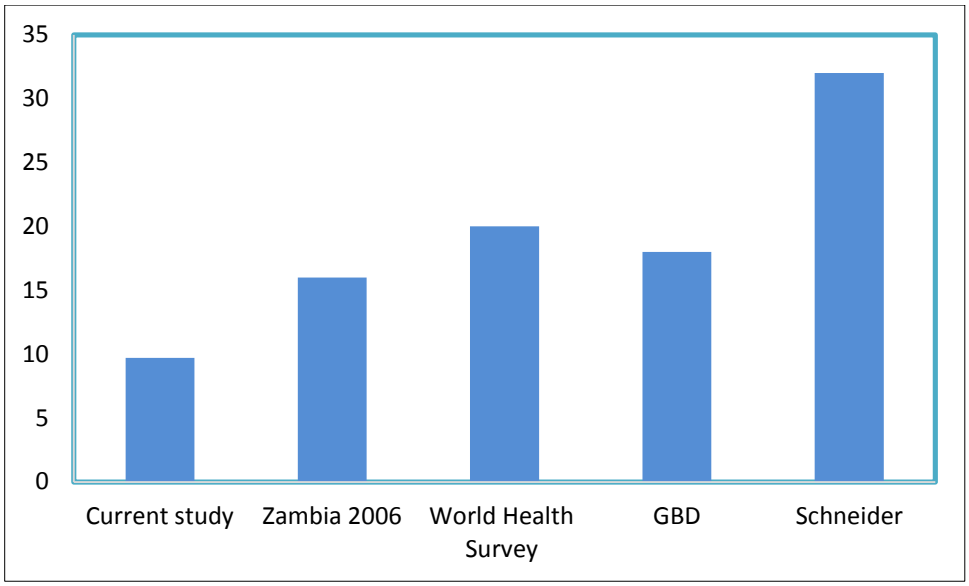


Figure 11: Comparison of overall disability rates with international and other studies (GBD = Global Burden of Disease study)

4.7.2.2 Comparison with rates of severe disability

In contrast to the large discrepancies in overall rate of disability, the proportion of those with severe disabilities, including those "Unable to do" in at least one domain in the current study, is comparable to both national and international data [10, 13, 96, 111] (Figure 12). The 4% rate for severe disability (including severe and unable to do) is somewhat higher than most rates reported elsewhere e.g. the World Health Survey estimate of 4% for severe disability and the Global Burden of Disease estimation of 3% having extreme or severe disability [96, 111]. Using the same methodology as in this study, a rate of 2.4% severe disability was reported in Zambia in 2006 [13]. The study by Schneider et al. that reported a high prevalence estimate of 30% for mild to moderate, only found a rate of 2.5% for severe disability [10]. Schneider (2009), when testing the WG Short Set, found that those with severe difficulties were more likely to identify themselves as being disabled than those with mild difficulties [7, 10].

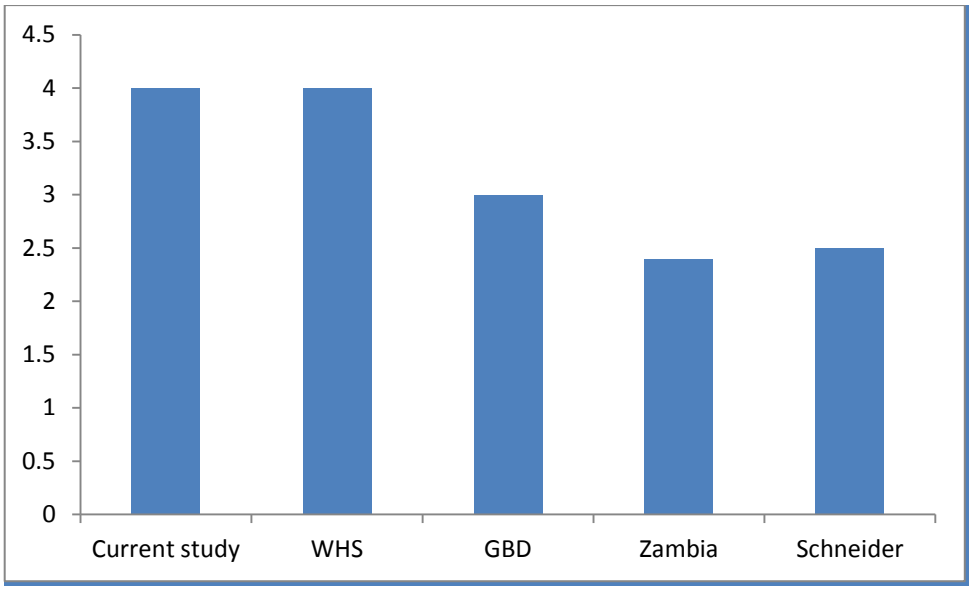


Figure 12: Comparison of rates of severe disability (current study data includes Confidence Intervals)

4.7.2.3 Implications

The literature suggests that three bands of disability prevalence rates emerge using the WG short questions: approximately 5% (2011 South African Census, Malawi and Mozambique), 9-15% (the current study, Zambia, Nicaragua) and a high rate of about 18-20% (US, Australia) [12, 13, 26, 30]. It is evident that even when using the WG questions, there is still a lower prevalence rate in the low income countries than in the high income countries. The assertion that disability prevalence is under-reported because of impairment-based surveillance systems is thus refuted [182].

Why are the South African rates generally so much lower than the international rates for overall disability? It is noteworthy that the prevalence of severe disability, as found in the current study, approximates not only the national rates but also the international rates for severe levels of disability. It could be that the rate of reporting of *mild to moderate* disability is more sensitive to different methodologies and screening instruments. We suggest that the national surveys appear to reliably identify those with more severe problems and if the CIs of the 5% rate are included, they would overlap with the 3.5-4.5% CIs for severe disability in this study. These contentions are supported by the similarity between the international prevalence rates for severe disability, both with this study and the South African national rates.

Further reasons for under-reporting in low and middle income countries have been ascribed to stigma associated with being disabled, which requires further exploration [90, 183, 184].

Great emphasis has been placed on obtaining comparable global data [41, 86, 96], however the results of this study show that the prevalence of disability, although comparable, is further influenced by contextual factors. According to Palmer and Harley (2012), using the WG Short Set has shown an average rate of 10-12%, suggesting a judicious threshold for functional difficulties and social context [241], and this falls within the CIs of the current study. Ustun et al. (2003) cautioned against the validity of heterogeneous population comparisons, as the severity of disability is subjective and could be influenced by culture, age and social context [96].

Small-scale population-based surveys appear to be more effective in capturing a greater range of people with disabilities. The Washington Group on Disability Statistics (2012) acknowledged that surveys tend to produce higher prevalence rates than censuses, and suggested that the context in which questions are posed might be responsible for the better response rate [242]. Other reasons are that surveys allow for more questions to be asked in a targeted context [242].

It must also be emphasised that the surveys purposively included the most economically vulnerable in the South African population. According to Ataguba et al. (2011), there is a greater burden of disability among lower socio-economic groups than in higher socio-economic groups in South Africa [243]. This could explain the higher prevalence rates found in this study that focused on under- resourced areas, with primarily Black inhabitants. Those who are poor are more prone to trauma, communicable disease and poor maternal and child care, and tend to have less access to health care [244] to combat the effects of ill-health. Disability in South Africa has also been associated with race, with higher prevalence rates being recorded among Blacks [6], which is similar to the results found in this study in that Nyanga has a predominantly Black population. According to Williams et al. (1997) race is an antecedent and determinant of socio-economic status and therefore part of the causal pathway by which this impacts on health [182]. Disability prevalence has also been found to be highest in the poorer provinces in South Africa [6]. Other studies have also shown a relationship between race, disability and socio-economic status [245]][246]. It was therefore not surprising that the prevalence rate in the current study was higher than the national averages.

4.7.3 Comparison of the general sample and those identified with disability

The sample of people with disability in the current study were older, more likely to be women and unemployed and had a lower income than the general sample. The trend of increased disability among women is well documented globally [14], [138] [247], [15], possibly due to the

higher incidence of non-communicable diseases, associated co-morbidities and increased life expectancy among women [248].

The older age of those screening positive for disability could be explained by the general association between age and disability i.e. decreasing function as one gets older [249]. The lower income associated with disability in this study is in contrast to that of Jelsma et al. (2008), who found household income to be higher in households with a disabled member, citing the disability grant as the reason [63]. Access to disability grants is discussed in Chapter 10.

4.7.4 Context – comparisons between the two sites

The expected negative impact of deprivation on functioning and disability was confirmed in the current study, thus supporting a Brazilian study that reported a strong linear relationship between increased income and decreased disability prevalence among older Brazilians [250]. However, the assertion that disability is more prevalent in less resourced communities was not borne out by the results of this study. A comparison of the prevalence rates across the two sites indicated that deprivation and socio-economic disadvantage are not the only drivers for disability. The prevalence rate in Oudtshoorn was almost half that of Nyanga, despite the Oudtshoorn sample being older, having less employed respondents and a lower median income. Clearly other contextual factors play a role and other studies in South Africa have reported similar results [251] . The CASE Disability survey (1999) also found higher prevalence rates among urban (6.3%) dwellers compared to rural (5.1%) dwellers [121]. The assertion that disability prevalence is higher in rural areas than urban areas is also not evident based on the results of this study. Oudtshoorn is a semi-rural town, which showed lower disability prevalence rates than Nyanga, a peri-urban area. The disability prevalence in Australia increased with relation to remoteness, with major cities showing much lower disability prevalence rates than the outer and remote regions [136]. The social environment is very different between the two areas in this study and this might account for the differences seen.

Adults in Nyanga constituted the largest group of people with disability identified in the current study, and 80% of those with disabilities were adults aged 15-60 years. This is surprising as this age group is generally the healthiest and most productive sector of society. Previous studies in Nyanga have shown similar prevalence patterns [233], which could suggest the consequence of urbanisation impacting on the economically active age groups. High levels of interpersonal violence fuelled by rapid urbanisation and socioeconomic disparities are much more evident in the urban context [182](38). This assertion is supported by the finding that

unintentional trauma was a significantly more common cause of disability in Nyanga (see Chapter 6).

The relatively smaller numbers of very severely disabled youth and elderly may be due to the high level of internal migration and the links that Nyanga residents might maintain with rural areas. As suggested by Evers (2012), children and the elderly may remain in the rural areas and we speculate that those with severe disabilities may move back to rural areas to be cared for by their extended families[252]. However, Oudtshoorn presented more people with severe disability compared to Nyanga. This result is also comparable to other studies conducted in South Africa [9, 104]. Access to health care for rural residents may be lacking and is a major contributing factor to the development of severe disability [9]. Studies in Brazil found similar results and hypothesised that those with severe disabilities in rural areas might migrate to urban areas for better access to health care [179].

Emphasis has been placed on obtaining comparable global data [41, 86, 253], however the results of this study show that the prevalence of disability, although comparable, is influenced at a micro-level but by contextual factors. This study demonstrated that two economically deprived areas showed very different patterns of disability. Persons with severe disabilities, representing the most vulnerable within societies, are of most relevance to policy makers and service providers, especially in resource-constrained environments where there are competing priorities. According to Helander (1992), it is reasonable to assume that persons with severe disabilities (A lot of difficulties and Unable to do) are dependent on others physically, economically, socially and psychologically, and would thus require a multidimensional approach to combat exclusion and facilitate participation in society [254].

The larger proportion of youth and elderly who were unable to do activities in Oudtshoorn speaks to the need to provide supportive, possibly home-based care services. This is particularly relevant in light of the general high care dependency ratio of 0.47 that reflects the caring load that is currently being taken on by adults in Oudtshoorn. The care dependency ratio was much higher in Oudtshoorn than in Nyanga (0.25), suggesting that service in this area should be geared toward caring for the carer as well.

In contrast, the large number of “Severe” responses, including adults, in Nyanga highlights the need for comprehensive rehabilitation services to ensure that people with disabilities reach their potential and can live active, productive lives. As the largest numbers of these adults lived in Nyanga, the preventative programmes need to target this age group, particularly risk factors related to trauma and infectious disease.

Those with mild disability (some difficulty) should benefit from short-term interventions and the provision of appropriate assistive devices, which would be the case for Nyanga. Economic empowerment initiatives should be a core service delivery component for people with disabilities, especially those living in Oudtshoorn.

4.8 Limitation of the methodology

There were several limitations in the methodology. Although dwelling type was used as the basis for stratifying the selection of participants, type of housing structure was not asked in the survey and it was not possible to test whether the sampling strategy was effective. In addition, the stratification was based on 2001 Census data and at this time, the number of people in formal dwellings had increased from 45.2% [6, 9] to 67.5% [7, 13, 31, 32]. It is likely that those living in informal dwellings were over-sampled in the study. The results may then be more applicable to the very deprived section of the Nyanga population.

Another weakness in the methodology was that the disability estimates are based on proxy reporting from informants. This often results in under-identification of subjective problems [255], such as mental and emotional problems, as these are not as readily apparent as physical or sensory disabilities such as visual or hearing impairment. It is acknowledged that the prevalence of depression and other mental disorders is likely to be under-reported.

Another limitation is that the WG questions ask whether the respondent experiences hearing problems, even when wearing a hearing aid, or problems with vision, even when wearing glasses. It might be that these functional problems have also been under-estimated. It is recommended that these screening questions be separated into problems with and without the aids. In addition, pain should be considered as an impairment which could result in functional limitations not covered by the WG Short Questions, as people with disabilities have shown a greater prevalence of pain and interference of pain on Activities of Daily Living [256].

4.9 Conclusion

Small-scale population-based prevalence studies are more appropriate for determining disability prevalence prior to service planning, since census information seems to exclude those with mild to moderate disabilities. Information from the current study can be used to target appropriate interventions. For example, services planned for Oudtshoorn should be

more tailored toward children and elderly with severe disabilities, whereas services for Nyanga should be tailored toward preventing severe disability and alleviating difficulties associated with mild to moderate disability in adults. Economic empowerment initiatives should be a core service delivery component for people with disabilities, especially those living in Oudtshoorn. It is thus evident that, irrespective of the measuring instrument and the conceptual framework used for disability, prevalence estimates are still very much dependent on context, culture and social environment.

5 People with disabilities who were interviewed: sample description

This chapter will focus on the following study objectives:

1. To compare the sample interviewed with the sample of PWS`s identified
2. To establish the prevalence and severity of disability, measured using the Washington Group Short Set of Questions on Disability across the two sites

5.1 Sample

A total of 645 people screened positive for having some sort of disability during the survey, and a convenience sample of 379 individuals agreed to complete the disability questionnaire (57.8%). The interviews were restricted to those 15 years or older as the questionnaires have not been validated for use in children. Despite repeated visits, the proportion from each area followed up was associated with site: 196 of the responders with disabilities were from Oudtshoorn (85.3% of those aged 15 years or older who were identified with disabilities in Oudtshoorn) and 183 from Nyanga (47.7% of those aged 15 years or older who were identified with disabilities in Nyanga; Chi-sq.=75.3 p<.001). Due to time and resource constraints, it was not possible to interview all those who were identified as having a disability as this would have required repeated visits. In the case of those unable to answer for themselves, proxy responses were used. In total 258 respondents answered on their own behalf and 121 proxy responses were gathered.

To determine to what extent the interviewed sample was representative of the population of those who screened positive in the survey, the characteristics of the population and the sample were compared. Of those who completed the disability questionnaire, 45.4% were men and gender was not significantly associated with being a member of the interviewed or screened group (Chi-sq.=2.25, p=0.134). There was no significant difference in the mean age of the positively screened sample and those who were interviewed (Table 10).

Table 10: Mean age in the positive-screened sample and the people with disabilities (PWD) who were interviewed

	Mean age (yrs)	SD	N	t-value	p
Oudtshoorn - screened positive	50.5	20.4	245		
Oudtshoorn PWD	51.7	18.8	196	0.636	0.526
Nyanga - screened positive	47.1	18.4	401		
Nyanga PWD	46	16.8	183	0.657	0.511

There was no difference in the proportion of people with some/severe disability between the screened group and the interviewed group as a whole (p=0.985), but there were fewer with severe disability in the screened sample in Oudtshoorn (p=0.025) and more with severe disability in the screened sample in Nyanga (p=0.023) (Table 11). Similarly, although the overall employment rate was the same as in the screened sample, the employment rate in the interviewed Nyanga sample was lower than the screened sample.

Table 11: Severity of disability and employment status in the positive-screened sample and the people with disabilities who were interviewed

	% of those screened (N=645)			**% of those interviewed** (N=375, missing=4)			**Chi-sq**	**p**
Severity	**Some**	**Severe**	**N**	**Some**	**Severe**	**N**		
Oudtshoorn	137	107	244	130	65	195		
	56.1%	43.9%		66.7%	33.3%		***5.32***	***0.025***
Nyanga	241	160	401	90	90	180		
	60.1%	40.9%		50.0%	50.0%		***5.17***	***0.023***
All Groups	378	267	645	220	155	375		
	58.6%	41.4%		58.6%	41.3%		.0004	0.985
Employment	**Yes**	**No**	**N**	**Yes**	**No**	**N**		
Oudtshoorn	29	150	179	22	79	101		

	16.2%	83.8%		17.9	82.1%		***1.35***	***0.245***
Nyanga	76	296	372	13	102	115		
	20.4%	79.6%		10.2%	89.8%		***4.9***	***0.027***
All Groups	105	446	551	35	181	216		
	19.5%	80.5%		16.2%	83.8%		0.8	0.258

5.2 Comparison of socio-demographic characteristics in the two sites

The people with disabilities (PWD) who were interviewed in Oudtshoorn were significantly older, and there were fewer men compared to those in Nyanga (Table 12). Almost three times as many Oudtshoorn residents were married or cohabitating. There was no difference in the number completing secondary school, but more respondents in Oudtshoorn had only three years or less of education. More of the Oudtshoorn respondents were employed, and as expected, fewer received disability grants. In all, 270 respondents in both sites received grants, of which 247 were disability grants and 23 were old-age pensions. More Oudtshoorn respondents reported severe disability (Chi-sq =10.722, p=0.001).

Table 12: Demographic data of people with disabilities who were interviewed in the two sites

	Oudtshoorn n=196	**Nyanga n=183**	**Test (p value)**
Mean age (SD) Range N	51.7 (18.8, 15-91 yrs) 183	46.0 (19.6, 15-91 yrs) 179	***T=-2.8, p=0.005***
Gender: Males N	37.10% 63	53.80% 86	***Chi-sq=8.98, p=0.003***
Employed (15-65 years) N	17.9% 22	10.5% 13	***Chi-sq= 3.95 p=0.047***
Completed 3 years or less years of schooling, N	16.4% 27	6.4% 7	***Chi-sq=6.09, p=0.014***

Married or cohabitating N	43.4% 76	15.1% 25	***Chi-sq = 32.89 p<0.001***
Disability grant N (missing=5)	68.0% 119	78.5% 128	***Chi-sq = 4.89 p=0.027***

Note: the percentages are of those who responded to the specific question

5.3 Functional limitations as measured by the WG Short Set

The Washington Group Short Set questions were used to identify those experiencing difficulties with functional activities due to an impairment or health condition. The frequency of those identifying difficulties across the impairments and functional limitstions were established, e.g by adding those presenting with some difficulty, alot of difficulty and unable to do. Walking was identified as the most frequent domain for experienced difficulties. This was followed by Seeing in Oudtshoorn and Remembering in Nyanga (**Error! Reference source not found.**).

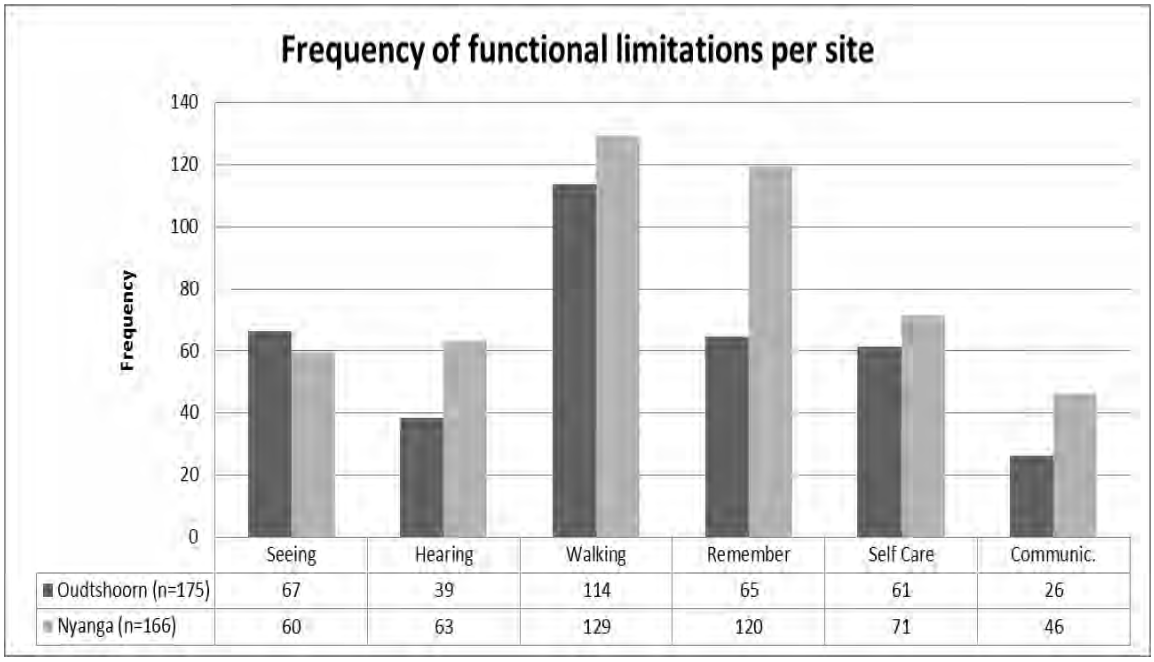


Figure 13: Functional limitations according to the WG Short Set in the two sites

Note: Total N=341, missing=38; Respondents could report multiple functional limitations. Information reported by the person identified with a disability.

As can be seen in Figure 14, the 95% CI for Walking in Oudtshoorn did not overlap with any of the other categories, which implies that there were significantly more respondents reporting this as a problem. In Nyanga, the CI of Walking and Remembering overlapped with each other but not with any other category. In other words these two categories had significantly more people reporting problems. In Oudtshoorn, the CI of the Communication category only overlapped with Hearing, otherwise all categories had overlapping CI. The domain of Remembering was the only one where there was no CI overlap between Oudtshoorn and Nyanga. It can therefore be concluded that Walking was significantly more prevalent than most other categories in both sites, Remembering was more prevalent in Nyanga and Communication was significantly less prevalent in Oudtshoorn compared to most other categories.

People with disabilities in the form of seeing, hearing and walking were older than those without these problems (Table 13).

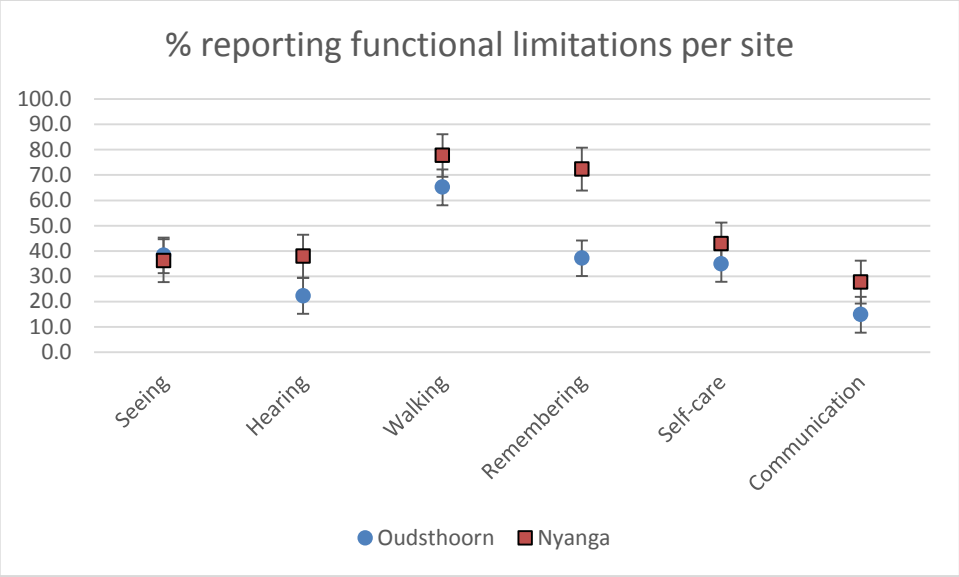


Figure 14: Percentage (and 95% CI) of functional limitations per site according to the WG Short Set

Table 13: Mean age across Functional limitations according to the WG Short Set

	Without the	Std.Dev.	With the disability	Std.Dev.	t-value	P

	disability				(df=339)	
Seeing	48.9	16.93	55.7	16.53	-3.62	*<0.001*
Hearing	49.6	16.15	55.7	18.50	-3.06	*0.002*
Walking	46.4	16.83	53.3	16.81	3.43	*0.001*
Remembering	52.2	17.58	50.5	16.49	0.91	0.365
Self-care	51.1	15.56	51.9	19.29	-0.44	0.658
Communication	51.4	16.08	51.3	20.51	0.06	0.949

Note: Total N=341, missing=38

5.4 Discussion

5.4.1 Sample

The significantly lower follow-up in Nyanga (48% compared to 85%) might be a cause for concern although there were few differences in the overall sample between those who screening positive for disability and those who were interviewed. The only difference was more respondents with severe disability and fewer people employed in the Nyanga sample compared to those screened. It is unclear why the follow-up in Nyanga was so much lower. The most likely reason is that those who were employed in the Nyanga sample were not reachable during the hours of interviewing, as evidenced by the decrease of 10% in the employment rate in the interviewed sample. This under-representation of employed PWD might also account for the drop in percentage of those with some disability, a similar decline of 10%. Although the enumerators were residents within the area, they were not happy to conduct interviews after 7pm at night for safety reasons, which could have influenced the follow-up of those identified with disabilities. Another cause could be the itinerant nature of an urban informal population, in that people living in informal settlements might be more inclined to change their dwelling places and be more difficult to follow up [257]. Due to the limitation of not having asked type of dwelling, it was not possible to test this hypothesis.

It is difficult to explain why the Oudtshoorn sample had fewer people with severe disability in the interviewed sample compared to those screened. A hypothesis could be that those with severe disability would require proxy reporting, and that very few caregivers were available to respond on behalf of those with severe disability, thereby failing to capture the full picture of needs among the most vulnerable.

The mean age of those interviewed in both areas was over 40 years with the majority being women. According to Peeters et al., this is the age when most women have difficulties with physical activity [258](58). The WHO (2011) has also estimated that 20% of those over the age of 70 years have some sort of disability, compared to 10% of the global population [259]. The increased life expectancy and increased burden of chronic diseases is in part responsible for the high prevalence of disability among the elderly ,especially in high income countries [260]. However, low income countries such as Mozambique reported a mean age of 36 years among those with disability [14]. Communicable diseases and lower life expectancy associated with low income countries are possible explanations for the younger mean ages of those with disability [260]. The mean ages of those interviewed in this study were similar to other middle income countries such as Brazil, showing highest prevalence rates in the age category of 35-44 years [19]. It is however interesting to note, that according to the 2001 Census, the prevalence of disability among males is greater in the younger age group, i.e. 15-24 (79). This was also seen in Australia, with women only surpassing men after the age of 60 years (80).

5.4.2 Comparison of the Functional Limitations (Washington Group Short Set Questions) across the sites

The prevalence of functional limitations in this study (where Walking was the most prevalent problem) is more comparable to international data than to national census data, which identified problems with Seeing as being most prevalent [6]. The prevalence of functional limitations was similar in the two areas.

Difficulties with walking emerged as the most prevalent disability type in both low income and high income countries [13, 14, 136]. Walking as an impairment is a confounder for other body function impairments that people with disabilities might experience, e.g. difficulty with breathing and tiredness impact on the ability to walk long distances and climbing stairs [261, 262]. These impairments might also impact on other functional activities such as dressing oneself and self-care, which, however, in this case did not emerge in the top three of impairments identified.

The significant difference in age among those with Walking difficulties compared to those without is similar to results of a 1998 English study, which reported the onset of knee and back pain to be in the older population [263]. Back pain was the most common musculo-skeletal disorder affecting those over 60 years, followed by knee pain for those over 65 years [263]. However, the mean age in the current study was lower. In 2010, the Global Burden of Disease Report confirmed that musculo-skeletal conditions were the second major cause of

disability globally [112]. It is likely that musculo-skeletal disorders such as knee and back pain could be the main contributing factors to the high prevalence of difficulties with Walking. This is discussed further in Chapter 8. A previous study conducted in Nyanga in 1986, showed a 18.3/1000 prevalence rate of locomotor disability within a sample of 2072, with most people using walking aids such as tripods, frames and walking sticks rate [244]. This prevalence rate of disability was much higher than the rate found among the White population group in Fish Hoek, which had an older population with a more severe level of disability and a higher use of walking aids [184]. This study already suggests that disability is more prevalent in lower socio-economic areas, however less severe.

The Oudtshoorn sample of PWD interviewed was older and included more women, more people with severe disability and more employed people than the Nyanga group. It was therefore not surprising that the nature of WG functional limitations were, with the exception of Walking, different between the two sites. Difficulties with seeing and osteoarthritis were identified as the most disabling conditions among the Coloured elderly in Cape Town, however very few identified themselves as being disabled [264], which could reflect the lower prevalence of disability in Oudtshoorn, which is also a primarily coloured population. The higher mean age in the sample could also account for the larger number of those with three or years less schooling, some of whom could be expected to be illiterate. Universal access to schooling was very limited for the majority of people with disabilities during the Apartheid years [156].

Seeing was rated as the second most prevalent problem in Oudtshoorn. This is comparable to the national census, which indicated that the majority of South Africans have some problem with vision [6]. The high prevalence of “difficulties with Seeing” could be associated with the lack of services in rural areas or, as found by Ntsoane et al. (2012), lack of awareness about the availability of services, specifically among people in rural areas [265]. The fact that the Oudtshoorn sample was older could also suggest the development of cataracts or a general decline of eyesight that could easily be rectified with glasses or surgery. Ntsonane et al. claimed that the likelihood of a high prevalence of eye problems in rural areas was linked to lack of services, physical inaccessibility, lack of awareness or cost associated with the services [265]. Eye care services including cataract removal should be available at all district hospitals [266], however attitudinal barriers such as fear of surgery and fatalistic view towards blindness in old age may limit the uptake for corrective surgery [267].

The second most prevalent impairment in Nyanga was Remembering and Concentrating. Mental health has emerged as the third highest burden of disease affecting South Africans [268]. A WHO report (2004) noted that psychiatric conditions account for at least five of the ten leading causes of disability and premature death [269]. Herman et al. (2009) found that the Western Cape had the highest prevalence of common mental disorders [134]. The Nyanga sample listed unintentional violence as a major cause of disability. Living in constant fear of violence can create anxiety, which could manifest itself as having problems with remembering and concentrating [270]. Mental health disorders were also related to urbanisation, with rural areas showing lower prevalence rates [271]. If the question relating to remembering and concentrating is taken as a proxy for mental health, it could explain the difference in prevalence rates obtained between Nyanga and Oudtshoorn in the current study. The developers of the WG Short Set assert that the question on difficulties with remembering and concentrating should identify people with cognitive impairments [117].

5.5 Limitation of the WG Short Set of Questions

A major limitation of the current study was the inability of the questions to properly identify children with disability. In the initial screening, over 100 children under three years old were identified as having disability, but most of them were described as being unable to walk and to do self-care and it was not possible to differentiate health problems from the normal developmental stages of childhood. The WG notes this limitation and states that the WG Short Set is not appropriate for use among children under 5 years old, as disability might be confused with normal age-related development [12]. The use of the WG Short Set in the national census means that children under 5 years with disability are not identified and thus services to this vulnerable group may be being neglected.

Another shortcoming of the screening questions is the lack of direct screening of mental health, particularly in the light of the reported high burden of disease due to mental disorders [268]. The WG developers suggest that Remembering be used as a proxy for problems in this area [117], but as many people with psychiatric disorders do not have specific problems with memory, the number of people with mental disorders may be underestimated by the screening tool and consequently in this study.

5.6 Conclusion and implications for service delivery

It is likely that the people with disabilities who were interviewed were generally representative of disabled people living in the survey area as a whole, with the proviso that the degree of disability might vary and that the Nyanga sample might represent the more severely disabled.

Walking difficulties, which were common to both areas, require specific intervention to ensure adequate participation of people with disabilities. Walking difficulties might also limit access to rehabilitation services if people are unable to travel to treatment centres. It is essential that home care be provided for those who are unable to travel to clinics and that those responsible for their care, whether physiotherapists or mid-level workers, be able to re-educate gait and prescribe appropriate assistive devices.

The prevalence of functional limitations appears to be linked to context, with cognitive difficulties being more common in an urban setting and preventable disabilities such as seeing in a rural area. The 2000 Norms and Standards developed for Primary Health Care facilities [272] do not prioritise eye care, which is evident in the current prevalence of visual difficulties. Seeing also emerged as the major functional limitation among people with disabilities in Mozambique, with the majority similarly having “some problem” rather than “unable to do” [14], also suggesting a lack of specific adaptive services. As only 28 of the 45 people who needed assistive devices for visual impairment received it (Chapter 11 deals with service provision) in the current study, the situation seems to be similar in our study and there seems to be a pressing need to improve the support available for those with visual impairment.

A three-pronged approach has been suggested as the most effective way of curbing the growing burden of chronic diseases in developing countries namely epidemiological surveillance, primary prevention and secondary prevention [273](88). Steyn et al. suggest that disability can be prevented or delayed by regular screening for complications associated with diabetes and hypertension at primary care level, e.g. screening for retinopathy and foot problems among patients with diabetes could prevent blindness and amputations leading to disability[273]. The 2007 Burden of Disease study for the Western Cape and the 2012 Strategic Plan for non-communicable diseases (2012) both raise the issue of better human resources at community level to facilitate the implementation of preventive and health promotion strategies [274, 275].

The use of the WG Short Set as the screening tool for disability in the national census also needs to be revisited as it appears to have serious deficiencies. These include the lack of mental health questions, the inability to report disability in children under the age of five years and the exclusion of those with well functioning hearing aids as having a disability,

The specific health conditions which contribute to the burden of disease in the two areas surveyed in the study are discussed in the next chapter.

6 Health conditions and life years lost due to disabilities

6.1 Introduction

Effective resource allocation and preventive strategies require information about which health conditions are associated with disability. This entails not only counting the number of people who have disability associated with each condition, but also establishing the "burden of disease" attributed to the health condition. This "burden" as it relates to disability may be measured in quality-adjusted life years (QALYs), which include mortality and morbidity in one single measure. QALYs are the years lived weighted by the quality of life in that time [276]. The "burden" includes the number of QALYs *lost* due to a condition (also termed healthy years of life lost, HYLL) and is a product of the number of people who have a disability associated with this condition, the length of time that the disability is present and the severity of the condition, as measured by a utility weight such as the EQ-5D index. This chapter sets out to establish which health conditions are associated with the greatest burden. Similar categories to those used by the Global Burden of Disease studies have been used to categorise the health conditions. The severity of a condition was established using the EQ-5D index scores, which were derived from large-scale valuation surveys [277]. The formula for calculating the HYLL is given in Section 3.5.5.

This chapter addresses the following objectives:
Using a convenience sample of people with disability, to identify which health conditions are responsible for the greatest "burden", as defined by Healthy Years of Life Lost due to disability, and to explore the health conditions that are responsible for different "burden" patterns in the two sites.

It is acknowledged from the outset that the health conditions identified may not be entirely accurate as they are based on self-report and the description of the disability and causes as reported by the research assistants. However, the post-coding of the descriptive data was done by two physiotherapists working together to reach consensus regarding either the probable underlying health condition or the stated health condition.

6.2 Health conditions as reported by the participants

Table 14: Health conditions reported by people with disabilities (N=266, missing=75)

Health condition	Number reporting	% of those reporting
Arthritis	48	18.0
Diabetes	28	10.5
Stroke	22	8.3
Cerebral palsy	20	7.5
Hypertension	19	7.1
Epilepsy	14	5.3
Asthma	12	4.5
Fracture	11	4.1
Amputation	9	3.4
HIV	9	3.4
Meningitis	7	2.6
Psychiatric	7	2.6
Tuberculosis	7	2.6
Blindness	5	1.9
Spinal cord injury	5	1.9
Traumatic brain injury	5	1.9
Hearing loss	4	1.5
Intellectual impairment	4	1.5
Back pain	3	1.1
Cardiac condition	3	1.1
Polio	3	1.1
Burns	2	0.8
Cancer	2	0.8
Obesity	2	0.8
Scoliosis	2	0.8
Brain injury	1	0.4
Cursed	1	0.4
Depression	1	0.4
Down's syndrome	1	0.4
Foetal Alcohol Syndrome	1	0.4
Headaches	1	0.4
Heart disease	1	0.4
Measles	1	0.4
Rheumatic fever	1	0.4
Spina bifida	1	0.4
Substance abuse	1	0.4
Swollen feet	1	0.4
Takahashi's disease	1	0.4
	266	

Not everyone was able to give a diagnosis or health condition. Some respondents reported more than one condition and others did not know their diagnosis. The most common conditions reported were those of non-communicable disease e.g. arthritis, diabetes, hypertension and stroke, followed by maternal and child conditions such as cerebral palsy (Table 14).

There were 42 respondents reporting musculo-skeletal conditions, which included responses related to joint pain, lower back pain and amputations, and these were similar in number in the two sites (OR=1.3; CI 0.7-2.5).

6.3 Perceived cause of disability

The underlying cause of the disability was categorised according to the Burden of Disease categories and was based on the reported cause of disability (Appendix 1) as well as the health conditions listed in Table 15. The category of maternal and child health was used for descriptors such as "I was born disabled", "It happened when I was a baby" and cerebral palsy. The category of communicable diseases included infectious conditions such as HIV, tuberculosis and meningitis. Trauma was divided into intentional (all person-to-person trauma) and unintentional (mostly motor vehicle and work-related accidents). The mental health category included depression, belief in spiritual causes of illness, substance abuse, epilepsy and schizophrenia. The category of non-communicable diseases included conditions such as hypertension, diabetes and obesity. Cancers were included in the neoplastic category, but as there were few, these were not included in the analyses.

Table 15: Causes of disability according to the Global Burden of Disease categories

	Oudtshoorn	Nyanga	Total	OR	CI	p
Non-communicable	**67**	**36**	**103**	**2.2**	***1.4 - 3.6***	***0.001***
Trauma - unintentional	27	31	58	0.8	0.5 - 1.4	0.426
Maternal and child	21	27	48	0.7	0.4 - 1.2	0.259
Musculoskeletal	24	18	42	1.3	0.7 - 2.5	0.421
Trauma - intentional	**8**	**25**	**33**	**0.3**	***0.1 - 0.6***	***0.002***
Communicable	14	15	29	0.9	0.4 - 1.9	0.732
Mental health	5	9	14	0.5	0.17 – 1.6	0.652

Neoplastic	1	4	5	0.2	0.03 - 2.1	0.194
Unclassified /missing	21	18	39			
Total	175	166	341			

Conditions as reported by respondents and post-coded (Oudtshoorn N=175, 21 missing or unable to code; Nyanga N=166, 18 missing or unable to code)

The highest number of respondents (30%) were identified as having non-communicable diseases as the main cause of their disability (Table 15). The respondents in Oudtshoorn were twice as likely to report this as a cause than the respondents in Nyanga (OR 2.24; p=0.001). The next category was unintentional trauma at 17% (especially transport accidents). Intentional trauma (mostly assault by unknown individuals) was less likely a cause in Oudtshoorn (OR 0.27; p=0.002). In subsequent analyses the eight categories were reduced to six, by moving musculo-skeletal causes to either intentional or unintentional trauma, and by moving neoplastic causes to the non-communicable category.

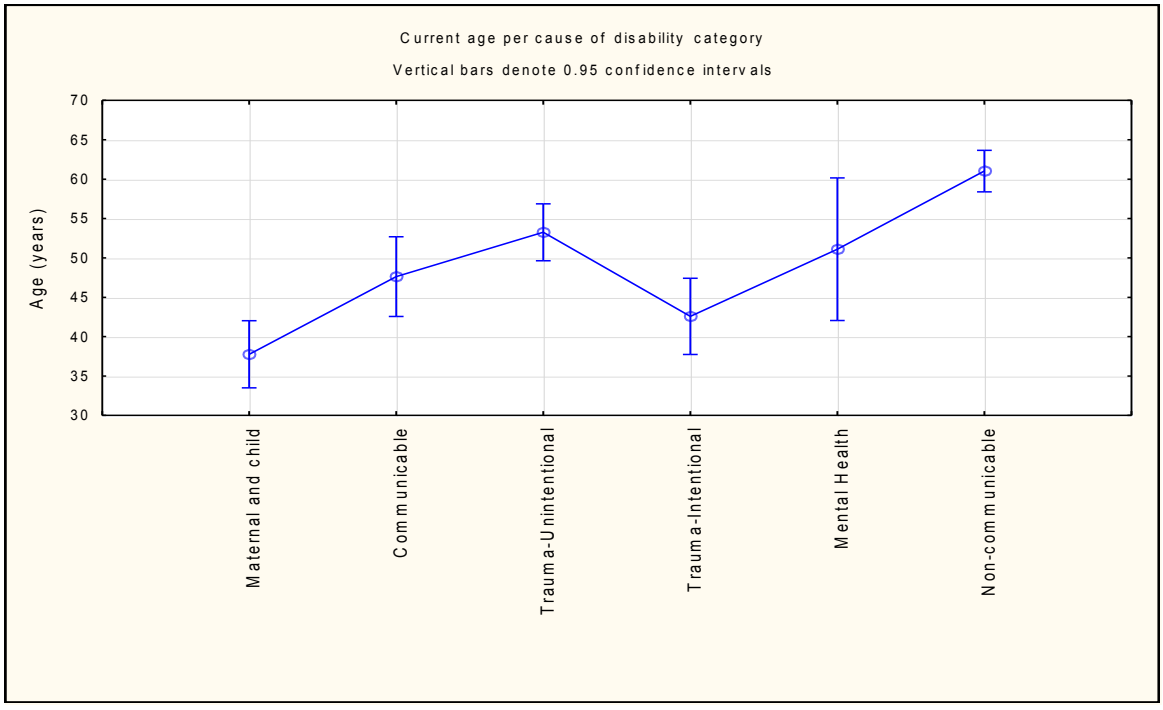


Figure 15: Mean age of respondents in various categories for cause of disability, (N=302)

A one-way Anova indicated that mean respondent age differed across the various causes of disability (F=21.339, p<.001). Respondents with maternal and child causes of disability were significantly younger, and those with non-communicable causes significantly older than in

most other categories (Figure 15 and Table 16). Those with intentional trauma were significantly younger than those with unintentional trauma.

The age of onset for each condition was significantly different ($F(5, 287)=52.306$, $p<0.001$). A post-hoc Tukey indicated that the age of onset for Maternal and child causes was significantly younger than that for all the other conditions, while the age of onset for non-communicable conditions was significantly older than the others, apart from Mental Health (Figure 16 and Table 16).

Table 16: Differences in mean age across six categories for cause of disability (P-values from Tukey tests, N=301)

Cause	Mean age	Maternal and Child	Communicable	Unintentional trauma	Intentional trauma	Mental health	Non-communicable
Maternal and child	37.8		0.039	0.000	0.684	0.091	P>0.001
Communicable	47.6	0.039		0.477	0.715	0.986	P>0.001
Unintentional	53.3	0.000	0.477		0.007	0.998	0.008
Intentional	42.6	0.684	0.715	0.007		0.575	P>0.001
Mental Health	51.1	0.091	0.986	0.998	0.575		0.302
Non-communicable	61.0	P>0.001	P>0.001	0.008	P>0.001	0.302	

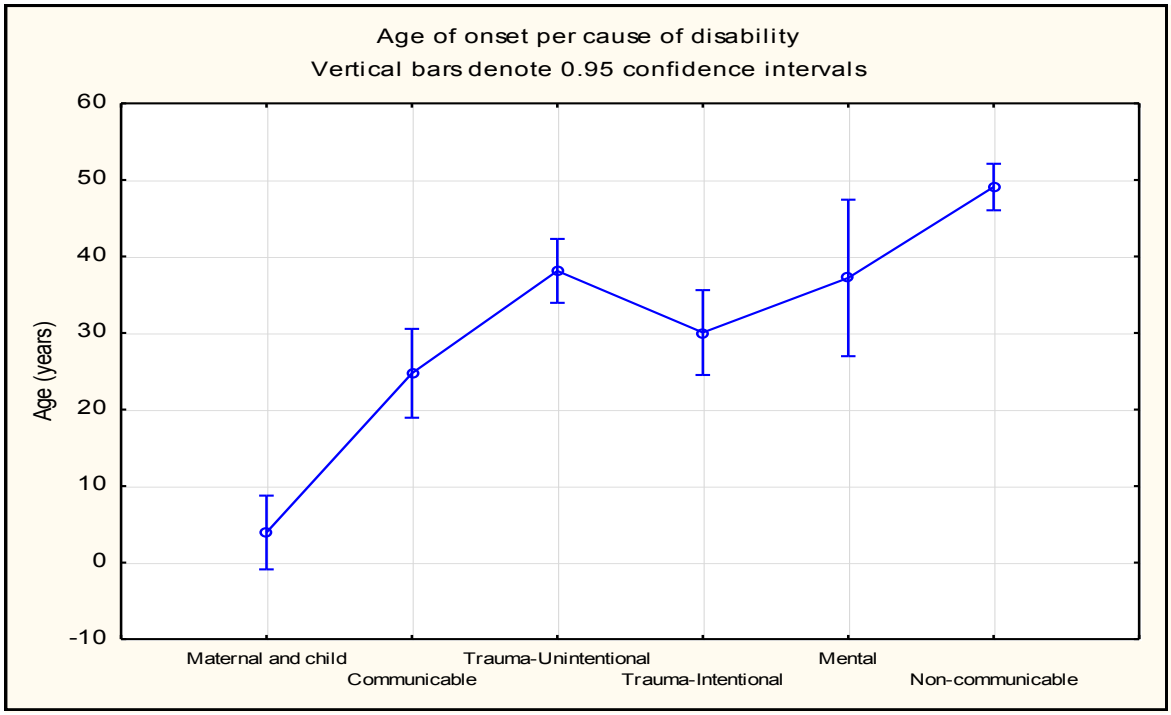


Figure 16: Age of onset per cause of disability

Table 17: Differences in mean age of onset across six categories for cause of disability (P-values from Tukey tests, N=301)

Cause	Mean Age	Maternal and Child	Communicable	Trauma unintentional	Trauma intentional	Mental health	Non-communicable
Maternal and child	3.9		*P<0.001*	*P<0.001*	*P<0.001*	*P<0.001*	*P>0.001*
Communicable	24.7	*P<0.001*		*0.003*	0.783	0.294	*P>0.001*
Unintentional	38.1	*P<0.001*	0.003		0.200	1.000	*P>0.001*
Intentional	30.1	*P<0.001*	0.783	0.200		0.833	*P>0.001*
Mental Health	37.2	*P<0.001*	0.294	1.000	0.833		0.241
Non-communicable	49.1	*P<0.001*	*P<0.001*	*P<0.001*	*P<0.001*	0.241	

6.4 Burden of disease – Healthy Years of Life Lost

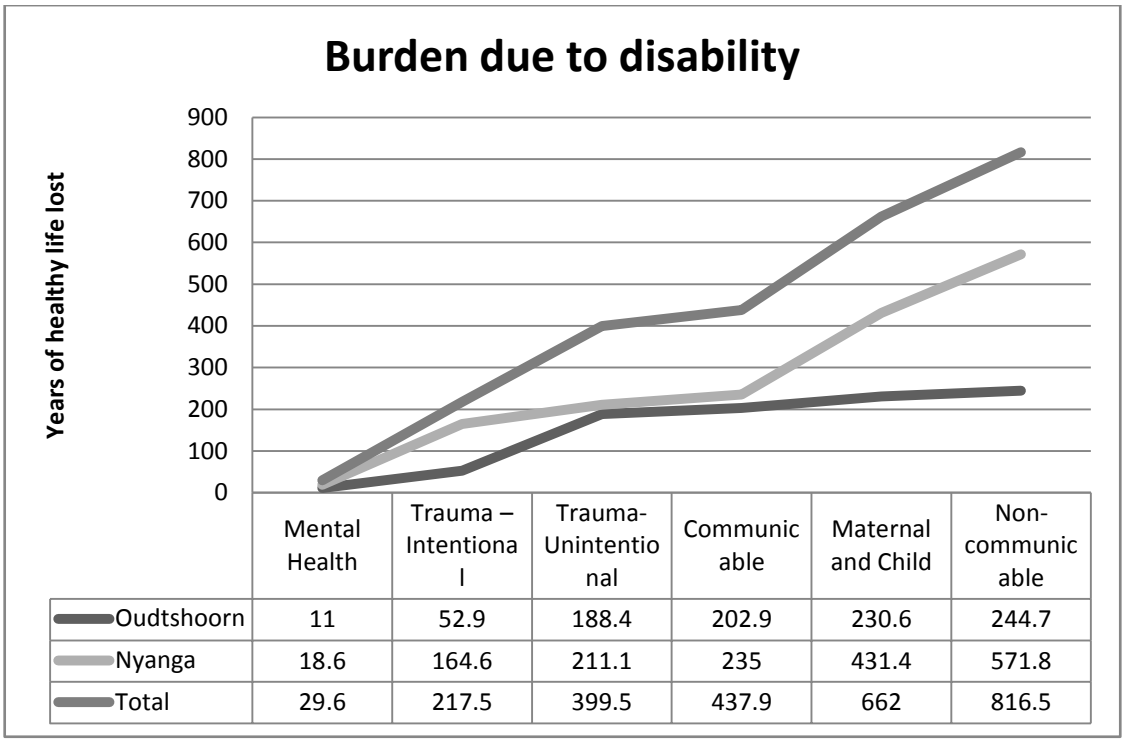
Non-communicable disease was the cause of the most years of healthy life lost, primarily due to the severe impact of the condition on HRQoL (Table 18). Second was Maternal and child conditions due to the extended length of time lived with the condition.

As can be seen in Figure 17, the burden of disability was lower across all conditions in Oudtshoorn, primarily due to the utility value which was higher in Oudtshoorn and consequently the 1-Index value was lower and contributed less to the HYLL. Oudtshoorn contributed 36% and Nyanga 64% to the total burden.

Table 18: Number of healthy years of life lost (HYLL) due to disability associated with six categories for cause of disability (N=301)

		Valid N	**Length of time**	SD of time	**Mean 1-Index**	SD of Index score	**Mean years HYLL**	**Total HYLL**	Std.Dev.
Non-communicable	Oudtshoorn	**68**	**10.7**	1.8	**0.40**	0.05	**3.6**	**244.7**	5.4
	Nyanga	**45**	**13.4**	1.9	**0.88**	0.05	**12.7**	**571.8**	11.8
	Total	**113**						**816.5**	
Communicable	Oudtshoorn	**15**	**25.6**	3.8	**0.49**	0.01	**13.5**	**202.9**	12.7
	Nyanga	**16**	**18.3**	3.5	**0.75**	0.1	**14.7**	**235**	19.7
	Total	**31**						**437.9**	
Trauma-Unintentional	Oudtshoorn	**32**	**14.7**	2.6	**0.39**	0.07	**5.9**	**188.4**	10.8
	Nyanga	**28**	**11.2**	2.5	**0.53**	0.07	**7.5**	**211.1**	9.3
	Total	**60**						**399.5**	
Trauma – Intentional	Oudtshoorn	**9**	**15.3**	4.9	**0.45**	0.13	**5.9**	**52.9**	6.3
	Nyanga	**25**	**14.7**	2.4	**0.55**	0.07	**6.6**	**164.6**	5.5
	Total	**34**						**217.5**	
Maternal and Child	Oudtshoorn	**18**	**38.9**	3.5	**0.36**	0.09	**12.8**	**230.6**	15
	Nyanga	**27**	**30.4**	2.4	**0.51**	0.07	**16**	**431.4**	17.8
	Total	**45**						**662**	
Mental Health	Oudtshoorn	**4**	**16.8**	7.4	**0.30**	0.2	**2.8**	**11**	1.8
	Nyanga	**6**	**12**	5.5	**0.45**	0.16	**3.1**	**18.6**	2.4
	Total	**10**						**29.6**	
Total Burden	Oudtshoorn	146						**930.5**	
	Nyanga	147						**1632.5**	
	Total	293						**2563.0**	
	Missing	48							

Calculated by summing the HYLL which are equal to length of time with disability [(Age-age of onset)*(1-index score)].



	Mental Health	Trauma – Intentional	Trauma-Unintentional	Communicable	Maternal and Child	Non-communicable
Oudtshoorn	11	52.9	188.4	202.9	230.6	244.7
Nyanga	18.6	164.6	211.1	235	431.4	571.8
Total	29.6	217.5	399.5	437.9	662	816.5

Figure 17: Burden due to cause of disability across sites

6.5 Discussion of health conditions

In severely deprived areas in a middle-income country, it might be expected that communicable diseases would contribute the most to the burden of disease attributed to disability. This was not the case, and in both areas, non-communicable diseases contributed several times larger than communicable disease. Compared to the Nyanga sample, the Oudtshoorn sample was more than twice as likely to have a non-communicable cause of disability and one-third as likely to have intentional trauma as a cause.

6.5.1 Use of Burden of Disease methodology

Conventional methods for quantifying disability in populations have mostly relied on cross-sectional censuses and surveys measuring prevalence of disability in a given period [53]. The data generated are helpful in defining the extent and demographic pattern of disabilities in a population, providing the basis for rehabilitative services. However, planning for preventive services and resource allocation require detailed information on the underlying diseases and injuries that cause disabilities. Resource allocation could be guided, for example, by an aim to reduce the number of HYLL due to disability. Although there is discomfort relating to the use of the word “burden”, it was coined by the Global Burden of Disease study and is used here as it

incorporates the important concept that disease does not simply result in years of life lost, but also in the loss of healthy life years due to disability. The use of the QALY / HYLL metric enables the researcher to compare the societal impact of a severe disability in an elderly person with, for example, a less severe disability in a child or the death of a young person.

Although Burden of Disease studies have been conducted in South Africa, these have only included the impact of mortality in the calculation of Disability Adjusted Life Years, a specific form of QALY [278]. The impact of the disability component was not factored in as there was little information regarding the prevalence and the utility attached to conditions associated with disability.

A further concern is that, as is fundamental to the ICF conceptual framework, disease does not cause disability but disability emerges from the interaction of health condition, environmental context and functional limitations. We therefore wish to clarify that the functional limitations and reduced HRQoL reported by the respondents is not causally related to the health condition, but may well be associated with it.

The discussion of this chapter will focus on the most prevalent conditions identified in both of the areas surveyed in the current study, and the implications for service planning.

The quadruple burden of disease experienced in South Africa is clearly evident in the causes of disability listed, with both areas reflecting post-transitional causes of disability [279]. Reddy (1998) suggested that the rapid demographic and economic transition in low and middle income countries is partly to blame for increased morbidity and mortality due to cardiovascular diseases [279]. The changes in dietary and lifestyle patterns (namely the higher intake of saturated fats and lower intake of unrefined carbohydrates) and the increase in physically undemanding pastimes are risk factors for the development of non-communicable diseases in both low and high income countries, and mostly among the urban poor [280, 281]. Non-communicable diseases, also referred to as chronic diseases of lifestyle, are a group of diseases that share common risk factors related to an exposure of poor lifestyle choices over a long period of time [282]. Diabetes, stroke and high blood pressure were the three main conditions in the current study. South Africa has the highest prevalence of diabetes and hypertension in Sub-Saharan Africa [273]. A cause for concern is that 90% of those with diabetes in South Africa have type 2 diabetes, which is a preventable disease These patterns of disease are prevalent among those with and without disability, and it is evident that greater resources need to be given to the prevention of primary and secondary disability. It is estimated that, without intervention, these three diseases will account for 80% of mortality

worldwide by 2015 [131]. Non-communicable diseases have also been cited as the main reason for hospitalisation, placing further stress on under-resourced health systems [214, 283]. Non-communicable diseases were significantly different in the two areas surveyed, with a much higher prevalence in Oudtshoorn. This is contrary to literature that suggests it is a consequence of rapid urbanisation [180, 257, 284]. However, the neo-liberal trade and economic policies make it easier for low and middle income countries to be flooded by cheaper, less healthy foods, thus creating the "health transition" evident in both sites [285, 286].

More respondents in Nyanga than in Oudtshoorn described maternal and child health causes of their disability, with cerebral palsy being the major condition in this category. This is unexpected in an urban setting, as children born in rural areas are disproportionately more likely to be born with a disability [128]. The 2011 Census also showed that most people who leave the Eastern Cape settle in the Western Cape, suggesting that people with disabilities might move from rural areas in search of better access to health care and opportunities. Many risk factors related to genetics, nutrition and service delivery have been attributed to maternal and child health outcomes. Of significance to this study is the pervasive effect of poor social and environmental conditions in impoverished communities [287]. This could explain why there was no significant difference between the two areas with regard to maternal and child health as a cause of disability. However, the attributable risk associated with context and sub-populations must be considered in strategies to improve maternal and child health outcomes [287]. A recommendation from the Western Cape Burden of Disease Reduction Project (2007) was a home-visiting intervention for new parents in high-risk areas (as defined by the multi-deprivation index) with the specific aim of improving parenting skills. Poor childhood development is a risk factor for mental health afflictions in later life [274].

The 2010 Burden of Disease Study showed that musculoskeletal conditions, diabetes and mental health conditions are among the leading causes of global disability [288]. Musculoskeletal conditions followed by hypertension were also more prevalent among those over the age of 50 years in other rural areas in South Africa [214]. Research has further shown the link between diabetes and musculoskeletal conditions, especially joint-related impairments, resulting in chronic disablement [18, 289]. This explains the high prevalence of arthritis in the musculoskeletal category in this study. Musculoskeletal conditions could also be outcomes associated with intentional and unintentional trauma, and should be viewed in conjunction with the other causes listed.

Almost three times as many people in Nyanga identified intentional trauma as the cause of their disability compared to Oudtshoorn. Interpersonal violence was rated among the top five causes of mortality among South African men [240]. A consequence of institutionalised racism in South Africa is internalised feelings of inferiority and low self-worth which, according to Bushman and Baumeister (1998), link to a propensity to violence [290]. The inequalities and huge disparities between the rich and the poor have also been cited as provoking questions of self-worth [291]. The mean age of those citing "intentional violence" as the cause of their disability is significantly younger than for any of the other causes listed, except for those attributing their disability to maternal and child health and communicable causes. The mean age suggests this to be a potentially economic active group, but with the high unemployment rate in South Africa (less than 60% employment [292]), frustration is inevitably fuelling the self-worth argument described above. The Western Cape Burden of Disease Report has also attributed the violence and unintentional trauma (accidents) to alcohol and drug abuse, with most of the alcohol-related violence occurring in areas with high levels of multiple deprivation and inequity, such as Nyanga [274].

Causes related to substance abuse, witchcraft and neoplasms were remarkably few. Although Oudtshoorn is a rural town, none of those interviewed related their disability to witchcraft. The only two respondents who did were from Nyanga, which might suggest that the belief is a cultural phenomenon rather than geographical. This refutes the view held by Saul and Phillips (1999) of a "rural cosmology" firmly based in traditional values and an "urban cosmology" which is held by people who have been "exposed to modernity in all its facets" [293].

6.5.2 The implications for service planning

It is evident that health promotion strategies aimed at reducing the risks of developing secondary complications for people with disabilities and improving their general health status should become a public health priority. The secondary complications that can develop from the high prevalence of diabetes among people with disabilities in Oudtshoorn will result in a higher risk of infection and poor healing of pressure sores. The exposure to high levels of intentional and unintentional trauma in Nyanga will fuel poor activity levels among people with and without disability, increasing the risk of obesity, hypertension and diabetes. Increased activity levels among the elderly presenting with musculo-skeletal conditions should also be encouraged to ensure active ageing. However, these strategies need a supportive environment. It is evident that a multi-faceted approach is required to address the major causes of disability within the two areas surveyed. Effective health promotion in South Africa is

dependent on collaboration across sectors, including health, housing, environmental, education and social development departments [294].

The impact of urbanisation is evident in both areas surveyed, with the causes of disability primarily being related to non-communicable diseases, and in Nyanga also to intentional trauma. Preventive strategies for disability need to consider the impact of urbanisation on populations.

7 Activity limitations and Participation restrictions (WHODAS-2)- Results and Discussion

The WHODAS-2 is a disability assessment instrument that is based on the conceptual framework of the ICF. This chapter describes the domains in which most people experienced difficulties in the two sites and examines whether demographic factors predict scores on the WHODAS-2. As participation is an essential outcome of rehabilitation, the relationship between this and the other domains of the WHODAS-2 is examined in more detail.

The WHODAS-2 measures the level of functioning across six domains (se Appendix IV). Domain scores are calculated using an algorithm designed by the WHO [295] based on Item Response Theory, in which items and level of severity are differentially weighted to obtain a composite score [295]. The psychometric properties of the WHODAS were examined post hoc and are presented in Chapter 10.

7.1 Results

7.1.1 Raw data

Oudtshoorn respondents generally scored better than Nyanga across all domains of the WHODAS-2 (Table 19), but more of them reported severe problems/unable to do on concentration, analysing, understanding spoken language, standing for long periods, walking long distances, washing, dressing, sexual activity, barriers in the world, living with dignity, and having financial resources.

Table 19: Responses to each question of the WHODAS-2

Site	Oudtshoorn			Nyanga	
		175	%	166	%
COGNITION					
Concentrate	**None**	**102**	**58.3**	**41**	**24.7**
	Mild	17	9.7	27	16.3
	Moderate	21	12.0	64	38.6
	Severe	22	12.6	17	10.2
	Extreme/cannot do	12	6.9	16	9.6
Remember	**None**	**89**	**50.9**	**30**	**18.1**
	Mild	24	13.7	32	19.3
	Moderate	24	13.7	54	32.5
	Severe	25	14.3	36	21.7
	Extreme/cannot do	11	6.3	12	7.2
Analyse	**None**	**93**	**53.1**	**23**	**13.9**
	Mild	28	16.0	38	22.9
	Moderate	16	9.1	55	33.1
	Severe	20	11.4	33	19.9
	Extreme/cannot do	17	9.7	15	9.0
Learn	**None**	**92**	**52.6**	**30**	**18.1**
	Mild	17	9.7	33	19.9
	Moderate	24	13.7	42	25.3
	Severe	21	12.0	33	19.9
	Extreme/cannot do	17	9.7	25	15.1
Understand spoken words	**None**	**129**	**73.7**	**65**	**39.2**
	Mild	11	6.3	34	20.5
	Moderate	14	8.0	43	25.9
	Severe	11	6.3	15	9.0
	Extreme/cannot do	8	4.6	6	3.6
Maintain a conversation	**None**	**121**	**69.1**	**70**	**42.2**
	Mild	16	9.1	24	14.5
	Moderate	13	7.4	35	21.1
	Severe	14	8.0	19	11.4
	Extreme/cannot do	10	5.7	13	7.8
GETTING AROUND					
Standing for long periods	**None**	**55**	**31.4**	**34**	**20.5**
	Mild	13	7.4	12	7.2
	Moderate	27	15.4	34	20.5
	Severe	38	21.7	32	19.3

	Extreme/cannot do	41	23.4	51	30.7
Sitting to standing	**None**	**54**	**30.9**	**36**	**21.7**
	Mild	20	11.4	16	9.6
	Moderate	36	20.6	46	27.7
	Severe	37	21.1	36	21.7
	Extreme/cannot do	27	15.4	29	17.5
Moving around in the home	**None**	**79**	**45.1**	**44**	**26.5**
	Mild	22	12.6	20	12.0
	Moderate	35	20.0	53	31.9
	Severe	25	14.3	31	18.7
	Extreme/cannot do	11	6.3	15	9.0
Getting out of the house	**None**	**74**	**42.3**	**38**	**22.9**
	Mild	28	16.0	21	12.7
	Moderate	34	19.4	52	31.3
	Severe	21	12.0	37	22.3
	Extreme/cannot do	16	9.1	13	7.8
Walking long distances	**None**	**36**	**20.6**	**22**	**13.3**
	Mild	17	9.7	7	4.2
	Moderate	20	11.4	26	15.7
	Severe	37	21.1	48	28.9
	Extreme/cannot do	64	36.6	59	35.5
SELF CARE					
Washing	**None**	**111**	**63.4**	**83**	**50.0**
	Mild	14	8.0	22	13.3
	Moderate	14	8.0	20	12.0
	Severe	14	8.0	23	13.9
	Extreme/cannot do	21	12.0	15	9.0
Dressing	**None**	**115**	**65.7**	**86**	**51.8**
	Mild	12	6.9	20	12.0
	Moderate	17	9.7	22	13.3
	Severe	13	7.4	20	12.0
	Extreme/cannot do	17	9.7	15	9.0
Eating	**None**	**142**	**81.1**	**137**	**82.5**
	Mild	17	9.7	6	3.6
	Moderate	7	4.0	9	5.4
	Severe	3	1.7	4	2.4
	Extreme/cannot do	5	2.9	4	2.4
Staying alone	**None**	**108**	**61.7**	**49**	**29.5**
	Mild	20	11.4	13	7.8
	Moderate	11	6.3	52	31.3
	Severe	7	4.0	20	12.0

	Extreme/cannot do	28	16.0	28	16.9
GETTING ALONG WITH PEOPLE					
Getting along with unknown people	**None**	**124**	**70.9**	**46**	**27.7**
	Mild	23	13.1	41	24.7
	Moderate	13	7.4	45	27.1
	Severe	6	3.4	21	12.7
	Extreme/cannot do	7	4.0	11	6.6
Maintaining friendships	**None**	**127**	**72.6**	**60**	**36.1**
	Mild	26	14.9	43	25.9
	Moderate	9	5.1	38	22.9
	Severe	6	3.4	12	7.2
	Extreme/cannot do	5	2.9	11	6.6
Getting along with people close to you	**None**	**135**	**77.1**	**112**	**67.5**
	Mild	26	14.9	22	13.3
	Moderate	4	2.3	18	10.8
	Severe	5	2.9	7	4.2
	Extreme/cannot do	2	1.1	5	3.0
Making new friends	**None**	**122**	**69.7**	**64**	**38.6**
	Mild	29	16.6	41	24.7
	Moderate	8	4.6	36	21.7
	Severe	5	2.9	11	6.6
	Extreme/cannot do	9	5.1	11	6.6
Sexual activities	**None**	**80**	**45.7**	**54**	**32.5**
	Mild	16	9.1	22	13.3
	Moderate	6	3.4	17	10.2
	Severe	8	4.6	16	9.6
	Extreme/cannot do	49	28.0	36	21.7
LIFE ACTIVITIES					
Household responsibilities	**None**	**70**	**40.0**	**25**	**15.1**
	Mild	28	16.0	29	17.5
	Moderate	33	18.9	57	34.3
	Severe	17	9.7	28	16.9
	Extreme/cannot do	25	14.3	24	14.5
Household tasks	**None**	**61**	**34.9**	**13**	**7.8**
	Mild	28	16.0	31	18.7
	Moderate	40	22.9	51	30.7
	Severe	18	10.3	37	22.3
	Extreme/cannot do	26	14.9	30	18.1

Household work	**None**	**55**	**31.4**	**12**	**7.2**
	Mild	24	13.7	23	13.9
	Moderate	40	22.9	55	33.1
	Severe	26	14.9	37	22.3
	Extreme/cannot do	28	16.0	34	20.5
Household work quickly	**None**	**45**	**25.7**	**11**	**6.6**
	Mild	19	10.9	12	7.2
	Moderate	33	18.9	47	28.3
	Severe	38	21.7	42	25.3
	Extreme/cannot do	36	20.6	47	28.3
Work	**None**	**18**	**10.3**	**29**	**17.5**
	Mild	7	4.0	8	4.8
	Moderate	10	5.7	11	6.6
	Severe	13	7.4	12	7.2
	Extreme/cannot do	6	3.4	16	9.6
Work tasks	**None**	**16**	**9.1**	**22**	**13.3**
	Mild	4	2.3	18	10.8
	Moderate	14	8.0	12	7.2
	Severe	12	6.9	6	3.6
	Extreme/cannot do	7	4.0	15	9.0
Finish work	**None**	**17**	**9.7**	**20**	**12.0**
	Mild	11	6.3	17	10.2
	Moderate	9	5.1	14	8.4
	Severe	8	4.6	10	6.0
	Extreme/cannot do	6	3.4	15	9.0
Work quickly	**None**	**16**	**9.1**	**17**	**10.2**
	Mild	5	2.9	9	5.4
	Moderate	10	5.7	20	12.0
	Severe	13	7.4	10	6.0
	Extreme/cannot do	7	4.0	20	12.0
PARTICIPATION					
Community activities	**None**	**76**	**43.4**	**55**	**33.1**
	Mild	26	14.9	25	15.1
	Moderate	30	17.1	38	22.9
	Severe	18	10.3	23	13.9
	Extreme/cannot do	21	12.0	22	13.3
Barriers in the world	**None**	**75**	**42.9**	**37**	**22.3**
	Mild	19	10.9	42	25.3
	Moderate	39	22.3	43	25.9
	Severe	27	15.4	33	19.9

	Extreme/cannot do	12	6.9	7	4.2
Living with dignity	**None**	**99**	**56.6**	**47**	**28.3**
	Mild	25	14.3	39	23.5
	Moderate	28	16.0	54	32.5
	Severe	13	7.4	18	10.8
	Extreme/cannot do	8	4.6	2	1.2
Health condition	**None**	**43**	**24.6**	**15**	**9.0**
	Mild	30	17.1	26	15.7
	Moderate	52	29.7	62	37.3
	Severe	39	22.3	40	24.1
	Extreme/cannot do	8	4.6	17	10.2
Financial resources	**None**	**47**	**26.9**	**24**	**14.5**
	Mild	37	21.1	18	10.8
	Moderate	30	17.1	57	34.3
	Severe	49	28.0	45	27.1
	Extreme/cannot do	9	5.1	17	10.2
Family problems with health care	**None**	**103**	**58.9**	**23**	**13.9**
	Mild	24	13.7	27	16.3
	Moderate	26	14.9	51	30.7
	Severe	15	8.6	51	30.7
	Extreme/cannot do	3	1.7	11	6.6
Relaxation/pleasure	**None**	**85**	**48.6**	**32**	**19.3**
	Mild	32	18.3	29	17.5
	Moderate	24	13.7	63	38.0
	Severe	16	9.1	23	13.9
	Extreme/cannot do	15	8.6	15	9.0

7.1.2 Total score

The mean percentage score of the entire sample was 38.0% (SD=5.4) (note that the higher the score, the worse the person's functional level) and there was no significant difference according to gender. The histogram in Figure 18 indicates that the scores were approximately

normally distributed.

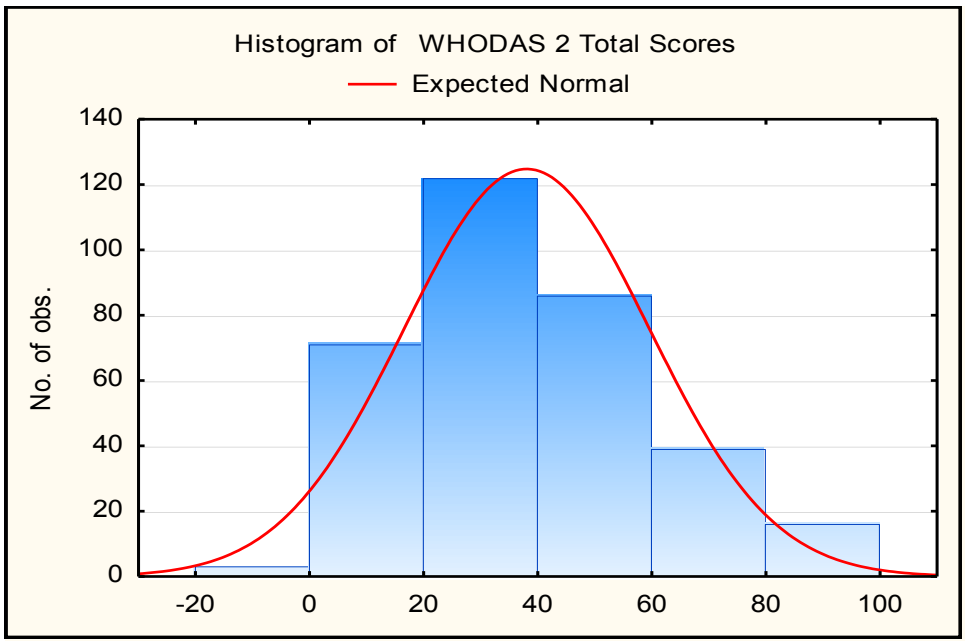


Figure 18: Histogram of the WHODAS-2 Total Scores (N=341)

As seen in Figure 19, there was a weak but significant correlation between age and WHODAS score (r=0.11, p=0.045).

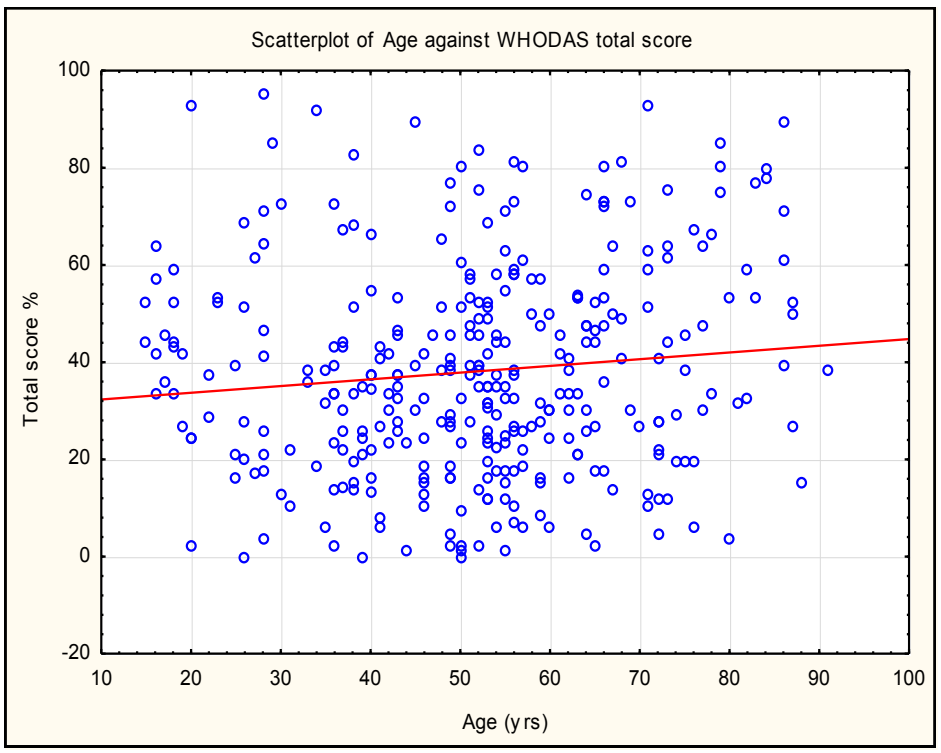


Figure 19: Scatterplot of the WHODAS total score versus respondent age (N= 341)

7.1.3 Domain scores

The mean domain scores were calculated using the algorithm- see Appendix (21.1)The mean domain score was lowest for Getting along with people (23.4; SD=27.08) and highest for Life Activities (55.29; SD=33.13) (Table 20 and Figure 21).

Table 20: Mean percentage scores for WHODAS-2 domains (N=338)

Domain	Mean %	Std.Dev.	N
Cognition	34.58	29.29	337
Getting around	51.78	32.55	335
Self-Care	26.40	30.37	334
Getting along with people	23.44	27.08	337
Life activities	55.29	33.13	338
Participation	35.59	19.60	335
Total WHODAS	38.07	21.55	337

The highest (worst) scores were for Getting Around (walking long distances, standing for long periods, moving from sitting to standing, moving in and out of the home) and Life Activities (household responsibilities, completing household tasks). A repeated measure ANOVA indicated that the mean scores were significantly different between the domains $F(5, 1645)=136.27$, $p>0.001$).

A post hoc Tukey indicated that most domains were significantly different from all the others (Table 21), with the exceptions of Getting Around and Life Activities (both high scores); Participation and Cognition (or Understanding) (both medium scores); and Self-care and Getting Along (both low scores).

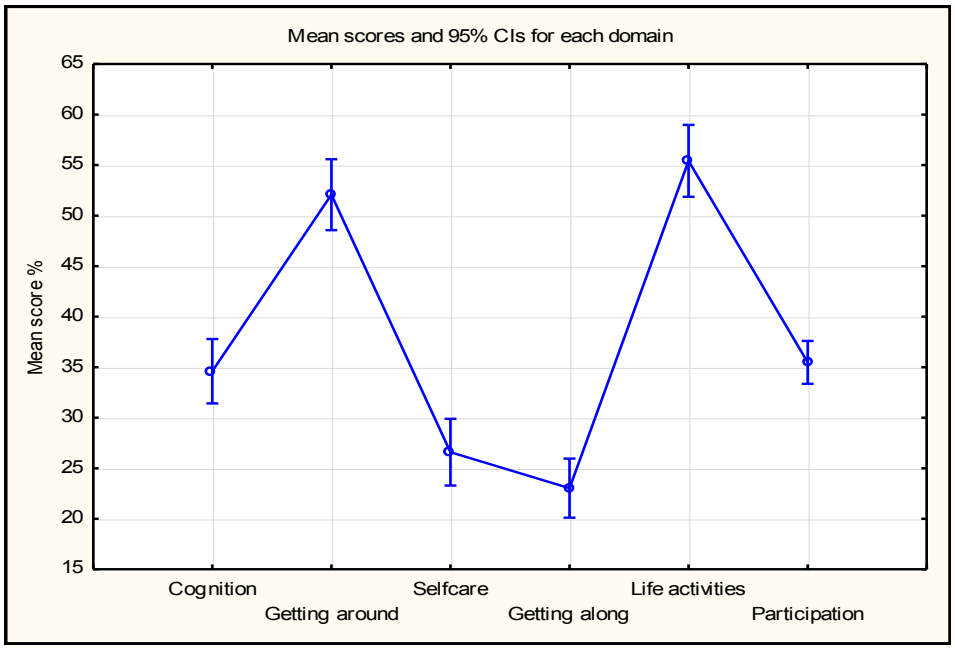


Figure 20: Mean scores and 95% CIs for each domain of the WHODAS-2 (N=338)

Table 21: Post hoc Tukey Comparison of mean scores of the different domains of the WHODAS-2 (N=334)

	Mean	Getting around	Self-care	Getting along	Life activities	Participation
Cognition	34.6	***p>0.001***	***p>0.001***	***p>0.001***	***p>0.001***	0.994
Getting around	52.1		***p>0.001***	***p>0.001***	0.292	***p>0.001***
Self-care	26.6			0.225	***p>0.001***	***p>0.001***
Getting along	23.0				***p>0.001***	***p>0.001***
Life activities	55.4					***p>0.001***

A significant correlation (0.71) was found between Understanding (includes spoken language, maintaining a conversation) and Getting along (e.g. making and maintaining friendships, sexual activity) as well as between Self-Care (e.g. washing, dressing, eating) and Life activities (e.g. completing household tasks, being able to work or attend school) (0.71), see Table 22 and Figure 21

Table 22: Pearson's correlation across domains of the WHODAS-2 (N=333, Missing=48)

	Mean	Std.Dev	Cognition	Getting around	Self care	Getting along	Life Activities
Cognition	34.58	29.29		0.26	0.58	***0.71***	0.58
Getting around	51.78	32.55	0.26		0.56	0.23	0.61
Self-care	26.40	30.37	0.58	0.55		0.55	**0.71**
Getting along	23.44	27.08	***0.71***	0.23	0.55		0.54
Life Activities	55.29	33.13	0.58	0.61	*0.71*	0.54	

All of the above correlations were significant at p<0.05.

The only significant difference in scores between genders was on the domain Getting along with people, on which men (28.1, SD=25.9) scored higher than women (20.6, SD=25.9; t=2.67, p=0.008).

Multiple regression analysis with the total WHODAS-2 score as dependent variable and the demographic variables of age, site (dummy variable) and gender (dummy variable) did not produce a good model and only accounted for 10% of the variance (adjusted r^2=0.105). However, the site (Nyanga) predicted a 10% increase in score (p<0.001) and each year of age added 0.17 to the score per year (p<.001). The contribution of gender was insignificant. The site (Nyanga) and all the other domains, apart from Self-care, predicted the Participation score reasonably well, with an adjusted r^2 of 0.55, after one outlier was removed from the analysis (Table 23). The relationship between the domains, including the correlations between the five domains and their standardised regression co-efficient, is present Figure 21

Table 23: Regression coefficients predicting Participation scores

	b*	Std.Err. of b	b	Std.Err. of b	t(325)	p-value
Intercept			0.6	0.14	4.36	<0.001
Site	0.09	0.04	0.17	0.07	2.28	0.023
Age	0.02	0.04	0	0	0.56	0.577
Cognition	0.24	0.06	0.19	0.05	4.25	<0.001
Getting around	0.18	0.05	0.13	0.04	3.57	<0.001
Self-care	0.08	0.06	0.06	0.05	1.28	0.201
Getting along	0.14	0.06	0.13	0.05	2.53	0.012
Life Activities	0.26	0.06	0.18	0.04	4.21	<0.001

***Standardised beta**

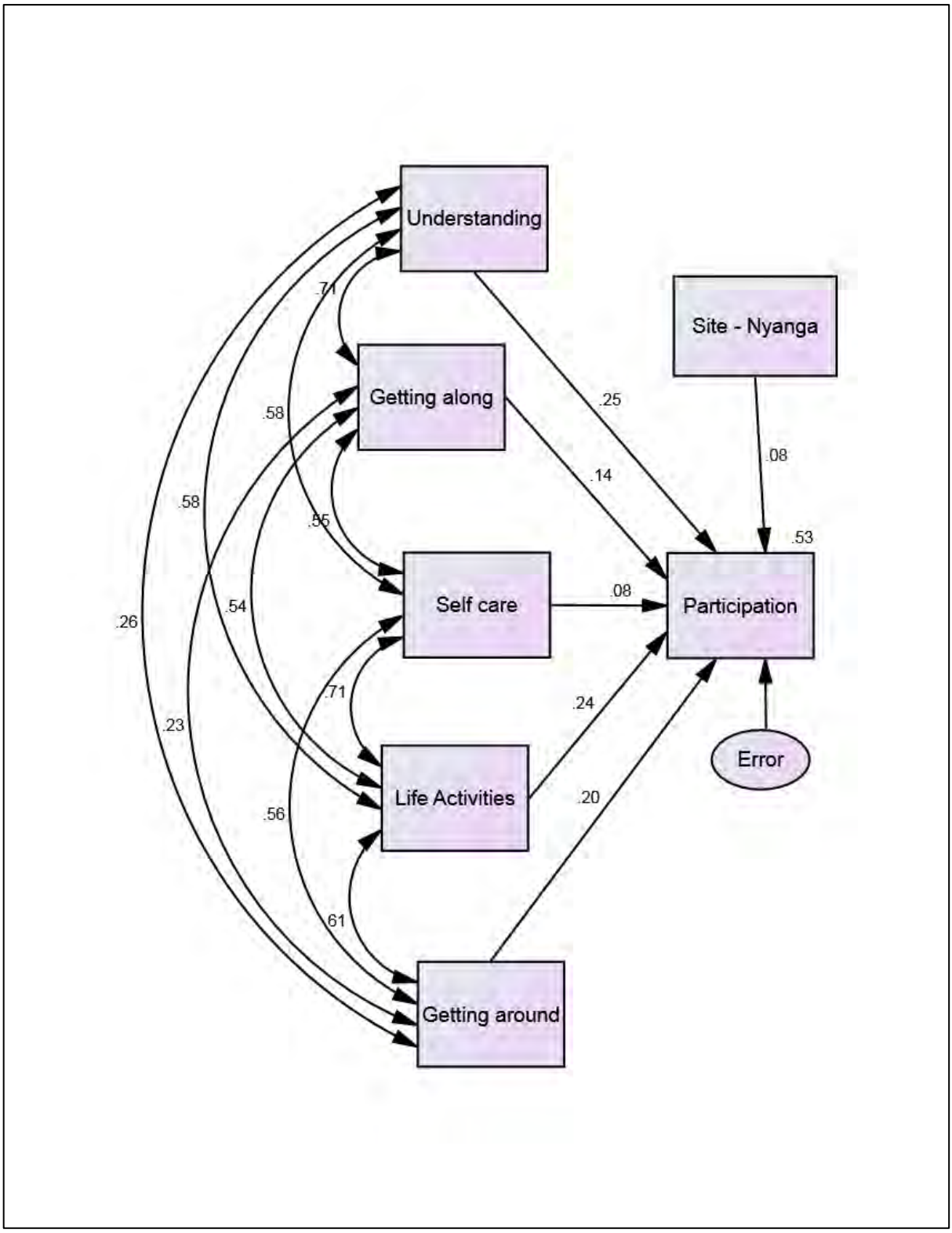


Figure 21: Model of relationship between the WHODAS-2 domains.

Correlations are given between the five domains, and the regression coefficients are between the domains and participation. The adjusted r^2 is over the Participation block. (Note this was

done without removal of the outlier. In addition, AMOS compensates for missing values; the results are thus slightly different from the Statistica ouput).

Nyanga respondents reported a significantly higher disability level (44.9 SD 19.7) (more than 10% higher) than the Oudtshoorn (31.6 SD21.3 participants (p=0.001).

Table 24 depicts the mean domain scores for Oudtshoorn and Nyanga, excluding the item for remunerated employment. The Nyanga respondents reported significantly more difficulties across all domains than the Oudtshoorn respondents (p<0.001). Both groups experienced most difficulties in the domains of Getting Around and Life Activities.

Table 24: Domain mean scores

Domain	Oudtshoorn Mean	Oudtshoorn SD	Nyanga Mean	Nyanga SD	t-value	df	p
Cognition	25.8	29.7	43.8	25.8	5.91	335	>.001
Getting around	47.3	33.0	56.6	31.5	2.65	333	0.008
Self-care	22.7	31.1	30.4	29.1	2.35	332	0.019
Getting along	15.0	25.1	32.4	26.3	6.22	335	>.001
Life Activities*	46.9	35.5	64.2	27.9	5.00	325.7	>.001
Participation	30.0	19.5	41.5	17.9	5.63	333	>.001

* Calculated using separate variances as these were significantly different.

The rank order of the WHODAS-2 domains was significantly correlated (Rho=0.829p=0.041) and the largest difference in score were in the domains of Cognition, Getting along and Life Activities. The smallest differences were between Getting Around and Self-care (Table 25).

Table 25: Rank order of the WHODAS-2 mean domain scores by site

Domain	Oudtshoorn		Nyanga		Difference
	Mean	Rank	Mean	Rank	(Nyanga-Oudtshoorn)
Understanding	25.8	3	43.8	4	18.0
Getting along	15.0	1	32.4	2	17.4
Life Activities	46.9	5	64.2	6	17.3
Participation	30.0	4	41.5	3	11.5

Getting around	47.3	6	56.6	5	9.3
Self-care	22.7	2	30.4	1	7.7

7.2 Summary of Results

The highest (worst) scores, both overall and for the individual sites, were for the domains of Getting Around and Life Activities, indicating that physical ability was the most affected. Demographic factors such as age, gender, and site did not predict the overall score well, although living in Oudtshoorn predicted a 10% decrease in score. Apart from Self-care, all the other domains predicted the Participation domain well, with Understanding emerging as the strongest predictor. The Oudtshoorn respondents reported better functioning as evidenced by lower scores in every domain, and their total mean score was more than 10% less than Nyanga. The rank order of domains according to score was similar in the two sites, with the greatest score difference seen for the domains of Understanding, Getting Along and Life Activities.

The correlations between the domains were all significant with the highest being between Self-care and Life Activities, and between Understandingand Getting Along. Gender and age were weak predictors of the overall WHODAS-2 scores. Nyanga consistently scored worse than Oudtshoorn across all domains, but particularly in the domains related to cognition and interaction with others, life activities and participation in the community.

7.3 Discussion

Understanding the degree of disability and ability to function within a context are essential for planning appropriate public health interventions [3]. This discussion section compares the functional level of the respondents to that reported in other studies, and relates the domains with most restricted functioning to the need for specific services. The relationship between activity and participation is also briefly discussed.

7.3.1 Comparison of overall score

The WHODAS-2 has been widely used to explore the experience of disability across different health conditions and in different contexts [18, 296-299]. The developers state that the WHODAS-2, in contrast to the WHOQOL, measures the level of functioning of an individual

within a specific life domain [197]. By using a score derived from item response theory, the global disability level or level of severity can be established [295]. The individual domain scores indicate the life domain in which the person with disability experiences the most barriers. Mont and Loeb (2008) demonstrated how activity limitation scores (ALS) and participation restriction scores (PRS) can be used to assess the effectiveness of programmes and policies for people with disabilities [3].

As expected, the global disability score of the group interviewed was higher than the mean score obtained in a general population sample, as they had been identified as having impairments. The mean score from the current study (38.0; SD=5.4) was considerably higher (worse) than that reported from a study conducted among persons with varying chronic diseases (24.8; SD=19.3)[297] and the mean score reported for older South Africans, especially those with lower educational level (22.2) and a low wealth quintile (23.0) [147]. Other studies have also affirmed the association between economic strain and moderate to severe disability [300].

Our respondents clearly had quite severe levels of disability. As was discussed in Chapter 5, the relative low response rate from Nyanga is likely to have biased the sample towards those with more severe disability.

7.3.2 Domain scores

Although Nyanga reported higher scores in every domain, the pattern of domain scores was remarkably similar in the two areas. Consistent with the finding that most respondents identified difficulties with walking during on the WG Short Set, the WHODAS-2 domains assessing the ability to walk or stand for long periods (Getting around) had the highest domain scores. Life Activities also scored highly. This domain includes activities related to household tasks and completing tasks quickly. Our study scores reflect quite severe activity limitations and are comparable to those of spinal cord patients, who reported the greatest limitations in the domains of Getting around, Life activities and Participation in society[209]. Post hoc Tukey analysis showed that there was no significant difference between the domains of Getting Around and Life activities in this study, suggesting that the constructs within these domains were similar and that problems in both of these areas may be primarily related to impairments of the locomotor system. In contrast, Getting Along was associated with Understanding, both of which may be related to impairments of cognitive functioning and communication. This could suggest that people who have concentration and speech problems find it difficult to

establish relationships with other people in these communities. This is especially worrying for the Nyanga area, where these problems are much worse.

Cambois (2005), using different instrumentation, concluded that demographic factors such as age, gender and context impact on self-reported activity and performance restrictions [137]. Age has been associated with higher domain scores for Life Activities and Getting Around, and lower scores for Getting Along [200], while Gallagher (2004) suggested that women experienced more difficulties with Life Activities and Getting Around [200]. In our study, however, context appeared to over-ride these factors as predictors of total score and participation in the community. Although the Oudtshoorn respondents were older than those in Nyanga, all their domain scores were lower. The multiple regression analysis also showed that site was a significant predictor of participation.

7.3.3 Participation

Regression analysis indicated that all domains except Self-care predicted the Participation score. The non-significant contribution of Self-care may be due to its high correlation with other domains. In poorer communities, access to rehabilitation services and assistive devices can improve Participation scores, which are strongly correlated to Self-Care scores due to the improved function. [3]. This indicates that there is a strong relationship between the domains that primarily measure activity limitations and those that measure participation. Thus in order to improve participation in community activities, the activity limitations related to the other domains need to be addressed. Only about half of the variance in participation was related to these functional problems, however, and the other 50% may be due to environmental factors such as access to services, appropriate training and attitudes of the community. Although individual rehabilitation is obviously necessary, environmental factors that restrict participation also need to be addressed.

It should be noted that Understanding was the best predictor of Participation. If concentration and language problems can be used as proxies for mental health issues, this could indicate the impact of mental health on participation.

7.3.4 Comparison between sites

Although the pattern of response was similar in the two areas, Nyanga respondents consistently scored higher than Oudtshoorn across all domains, suggesting that they were more disabled than those living in Oudtshoorn. This phenomenon reiterates the social model of disability that highlights the disabling impact of the environment rather than the impairment. In a study using the ICF Checklist, Maart et al. (2007) found that people with

disabilities living in informal settlements in an urban area experienced more environmental barriers than those in rural areas [36]. Chang et al. (2014) found that people with stroke who had access to *products and technology for personal indoor and outdoor mobility and transportation (e120)* had better WHODAS-2 scores [301].

The largest difference between the two sites were on the domains of Understanding and Getting Along'. Aspects related to concentration, learning, communication and thinking activities might be more affected in people with mental illness or substance abuse. Andrews et al. (2009) found that people with mental disorders had higher (worse) scores on the WHODAS-2 than those with physical disorders [302].

Two different factors may contribute to disability in Nyanga. The major causes of disability in Nyanga were non-communicable diseases and unintentional trauma and this might account for the large numbers of respondents reporting problems with locomotion and activities of daily living. Motor vehicle accidents and violence could be major causes of head injuries and lower limb fractures affecting long-term mobility and cognition. The possibly more worrying factor contributing to disability in Nyanga may be the systemic poor mental and social health related to living in a deprived urban township. A high rate of psychosocial problems resulting in morbidity and disability has been linked to increasing urbanisation, as has been experienced by the Nyanga population [257, 303]. Such psychosocial problems may be not only the cause of the intentional and unintentional trauma related to the high levels of substance abuse in the area [16], but may also explain the large between-site differences in Understanding, Getting along and Participation.

7.3.5 Implications for service delivery

The level of functional limitations reported was higher than other comparable groups and highlights the need to provide adequate rehabilitation services to people with disabilities. In high income countries, it is likely that people with severe functional limitations would receive either institutional care or well-structured community and home-based support. This is not the case in Nyanga, particularly for rehabilitation services. Rouillard et al. (2012) reported that although short-term rehabilitation care for patients post-stroke was comparable to that reported in international studies in terms of length of stay in rehabilitation centres and care received, 10% of patients had no further contact with healthcare services after discharge. They also identified excessive strain in over 50% of the caregivers. The high care dependency ratio in Oudtshoorn and the small number living within dwellings in Nyanga may highlight the need for additional health and rehabilitation support to both people with disabilities and their

caregivers. This support will require expertise in re-education of physical abilities and (especially in Nyanga) intervention to improve the mental health of the individuals and the community. Support groups for people with disability that are run by trained staff such as occupational therapists might reduce the isolation of people with disabilities in Nyanga who reported far more problems with Getting Along than their counterparts in Oudtshoorn.

A holistic view of health services is thus necessary in Nyanga to prevent disability and to address the difficulties experienced with mobility and learning. Support initiatives should be implemented at school level, with home and community support provided to improve functioning at home and participation. Initiatives to improve universal access for people with disabilities should address the difficulties in Getting Around in both areas.

The WHODAS-2 can be useful in assessing needs for services and in monitoring the impact of services at population or client level in a clinical setting. The needs identified in this study among persons with disability suggest that the Western Cape still has a long way to go in reorienting environments to be inclusive and supportive of people with disabilities.

8 Quality of Life: Results and Discussion

8.1 WHOQOL.BREF

Quality of life (QoL) has become a major outcome measure for exploring the impact of disability and disease from the individual's perspective. QoL is conceptualised by the WHO as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern."[238].

The purpose of this chapter is:

- To describe the impact of disability on perceived quality of life
- To assess for differences in perceived quality of life between the two sites
- To assess whether place of residence (site) is a determinant of perceived quality of life

The WHOQOL-BREF consists of 26 items that are combined using a scoring algorithm to establish an overall score as well as scores in four domains: Physical, Psychological, Social and Environmental. As the internal consistency of the instrument as a whole was high (see Chapter 10), parametric statistics were used to analyse the full data set. The internal consistency of some of the domains was unsatisfactory in the Afrikaans version used mainly in Oudtshoorn, however, so non-parametric statistics were used to analyse the domain data.

8.1.1 Responses to each question

The responses to each question asked in each domain are listed in Table 26.

Table 26: Raw data of the WHOQOL-BREF

			Oudtshoorn N=175		Nyanga N=141		Total	N=316
Domain	Question		N	%	N	%		
	How would you rate your quality of life?	**Very poor**	**9**	**5.10%**	**16**	**11.40%**	**25**	**7.90%**
		Poor	**26**	**14.90%**	**46**	**32.90%**	**72**	**22.90%**
		Neither poor not good	58	33.10%	46	32.90%	104	33.00%
		Good	73	41.70%	30	21.40%	103	32.70%
		Very good	9	5.10%	2	1.40%	11	3.50%
	How satisfied are you with your health?	**Very dissatisfied**	Not asked*		**28**	**20.00%**	**28**	**20.00%**
		Dissatisfied			**47**	**33.60%**	**47**	**33.60%**
		Neither satisfied nor dissatisfied			**42**	**30.00%**	**42**	**30.00%**
		Satisfied			21	15.00%	21	15.00%
		Very satisfied			2	1.40%	2	1.40%
Physical	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	**Not at all**	12	6.90%	20	14.30%	32	10.20%
		A little	37	21.30%	39	27.90%	76	24.20%
		A moderate amount	43	24.70%	41	29.30%	84	26.80%
		Very much	**76**	**43.70%**	**33**	**23.60%**	**109**	**34.70%**
		An extreme amount	**6**	**3.40%**	**7**	**5.00%**	**13**	**4.10%**
Physical	How much do you need any medical treatment to function in your daily life?	**Not at all**	36	20.70%	23	16.70%	59	18.90%
		A little	33	19.00%	59	42.80%	92	29.50%
		A moderate amount	38	21.80%	37	26.80%	75	24.00%
		Very much	**50**	**28.70%**	**18**	**13.00%**	**68**	**21.80%**
		An extreme amount	**17**	**9.80%**	**1**	**0.70%**	**18**	**5.80%**
Physical	Do you have enough energy for everyday life?	**Not at all**	**7**	**4.20%**	**12**	**8.60%**	**19**	**6.20%**
		A little	**4**	**2.40%**	**31**	**22.10%**	**35**	**11.40%**
		A moderate amount	47	28.00%	51	36.40%	98	31.80%
		Very much	96	57.10%	41	29.30%	137	44.50%
		An extreme amount	14	8.30%	5	3.60%	19	6.20%
Physical	How well are you able to get around?	**Very poor**	**34**	**19.70%**	**27**	**19.60%**	**61**	**19.60%**
		Poor	**41**	**23.70%**	**41**	**29.70%**	**82**	**26.40%**
		Neither poor not good	41	23.70%	40	29.00%	81	26.00%
		Good	37	21.40%	29	21.00%	66	21.20%
		Very good	20	11.60%	1	0.70%	21	6.80%
Physical	How satisfied are you with your sleep?	**Very dissatisfied**	**23**	**13.30%**	**9**	**6.40%**	**32**	**10.20%**
		Dissatisfied	**31**	**17.90%**	**21**	**15.00%**	**52**	**16.60%**
		Neither satisfied nor dissatisfied	50	28.90%	58	41.40%	108	34.50%
		Satisfied	51	29.50%	48	34.30%	99	31.60%
		Very satisfied	18	10.40%	4	2.90%	22	7.00%
Physical	How satisfied are you with your ability to perform your daily living activities?	**Very dissatisfied**	**14**	**8.00%**	**19**	**13.70%**	**33**	**10.50%**
		Dissatisfied	**33**	**19.00%**	**46**	**33.10%**	**79**	**25.20%**
		Neither satisfied nor dissatisfied	23	13.20%	56	40.30%	79	25.20%
		Satisfied	86	49.40%	17	12.20%	103	32.90%
		Very satisfied	18	10.30%	1	0.70%	19	6.10%
Physical	How satisfied are you with your capacity for work?	**Very dissatisfied**	**25**	**14.50%**	**38**	**27.10%**	**63**	**20.10%**
		Dissatisfied	**39**	**22.50%**	**37**	**26.40%**	**76**	**24.30%**
		Neither satisfied nor dissatisfied	39	22.50%	47	33.60%	86	27.50%
		Satisfied	63	36.40%	15	10.70%	78	24.90%
		Very satisfied	7	4.00%	3	2.10%	10	3.20%
Psychological	How much do you enjoy life?	**Not at all**	**20**	**11.40%**	**18**	**13.20%**	**38**	**12.20%**

		A little	**25**	**14.30%**	**23**	**16.90%**	**48**	**15.40%**
		A moderate amount	46	26.30%	61	44.90%	107	34.40%
		Very much	61	34.90%	24	17.60%	85	27.30%
		An extreme amount	23	13.10%	10	7.40%	33	10.60%
Psychological	To what extent do your feel your life to be meaningful?	**Not at all**	**8**	**4.70%**	**10**	**7.20%**	**18**	**5.80%**
		A little	**11**	**6.40%**	**10**	**7.20%**	**21**	**6.80%**
		A moderate amount	54	31.40%	42	30.20%	96	30.90%
		Very much	78	45.30%	73	52.50%	151	48.60%
		An extreme amount	21	12.20%	4	2.90%	25	8.00%
Psychological	How well are you able to concentrate?	**Not at all**	**7**	**4.00%**	**9**	**6.50%**	**16**	**5.10%**
		A little	**9**	**5.20%**	**23**	**16.50%**	**32**	**10.30%**
		A moderate amount	32	18.50%	62	44.60%	94	30.10%
		Very much	98	56.60%	35	25.20%	133	42.60%
		An extreme amount	27	15.60%	10	7.20%	37	11.90%
Psychological	How satisfied are you with yourself?	**Very dissatisfied**	**31**	**18.00%**	**23**	**16.40%**	**54**	**17.30%**
		Dissatisfied	**49**	**28.50%**	**37**	**26.40%**	**86**	**27.60%**
		Neither satisfied nor dissatisfied	33	19.20%	55	39.30%	88	28.20%
		Satisfied	53	30.80%	22	15.70%	75	24.00%
		Very satisfied	6	3.50%	3	2.10%	9	2.90%
Psychological	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Never	21	12.10%	11	7.90%	**32**	**10.30%**
		Seldom	21	12.10%	14	10.10%	**35**	**11.20%**
		Quite often	38	22.00%	42	30.20%	80	25.60%
		Very often	**71**	**41.00%**	**60**	**43.20%**	131	42.00%
		Always	**22**	**12.70%**	**12**	**8.60%**	34	10.90%
Social	How satisfied are you with your personal relationships?	**Very dissatisfied**	**16**	**9.20%**	**15**	**11.90%**	**31**	**10.40%**
		Dissatisfied	**33**	**19.10%**	**17**	**13.50%**	**50**	**16.70%**
		Neither satisfied nor dissatisfied	40	23.10%	38	30.20%	78	26.10%
		Satisfied	76	43.90%	51	40.50%	127	42.50%
		Very satisfied	8	4.60%	5	4.00%	13	4.30%
Social	How satisfied are you with your sex life?	**Very dissatisfied**	**5**	**2.90%**	**19**	**19.80%**	**24**	**8.90%**
		Dissatisfied	**17**	**9.80%**	**11**	**11.50%**	**28**	**10.40%**
		Neither satisfied nor dissatisfied	20	11.50%	26	27.10%	46	17.00%
		Satisfied	101	58.00%	26	27.10%	127	47.00%
		Very satisfied	31	17.80%	14	14.60%	45	16.70%
Social	How satisfied are you with the support you get from your friends?	Very dissatisfied	**17**	**12.90%**	**7**	**5.10%**	**24**	**8.90%**
		Dissatisfied	**14**	**10.60%**	**7**	**5.10%**	**21**	**7.80%**
		Neither satisfied nor dissatisfied	23	17.40%	58	42.00%	81	30.00%
		Satisfied	57	43.20%	60	43.50%	117	43.30%
		Very satisfied	21	15.90%	6	4.30%	27	10.00%
Environmental	How safe do you feel in your daily life?	**Not at all**	**18**	**10.30%**	**15**	**10.80%**	**33**	**10.50%**
		A little	**22**	**12.60%**	**27**	**19.40%**	**49**	**15.70%**
		A moderate amount	42	24.10%	54	38.80%	96	30.70%
		Very much	67	38.50%	40	28.80%	107	34.20%
		An extreme amount	25	14.40%	3	2.20%	28	8.90%
Environmental	How healthy is your physical environment?	**Not at all**	**11**	**6.30%**	**15**	**10.70%**	**26**	**8.30%**
		A little	**9**	**5.10%**	**16**	**11.40%**	**25**	**7.90%**
		A moderate amount	32	18.30%	56	40.00%	88	27.90%
		Very much	96	54.90%	48	34.30%	144	45.70%
		An extreme amount	27	15.40%	5	3.60%	32	10.20%
Environmental	Have you enough money to meet your needs?	**Not at all**	**10**	**5.80%**	**92**	**66.20%**	**102**	**32.70%**
		A little	**21**	**12.10%**	**22**	**15.80%**	**43**	**13.80%**
		A moderate amount	38	22.00%	18	12.90%	56	17.90%

		Very much	70	40.50%	7	5.00%	77	24.70%
		An extreme amount	34	19.70%	0	0.00%	34	10.90%
Environmental	How available to you is the information that you need in your day-to-day life?	**Not at all**	**83**	**48.00%**	**17**	**12.10%**	**100**	**31.90%**
		A little	**23**	**13.30%**	**45**	**32.10%**	**68**	**21.70%**
		A moderate amount	32	18.50%	61	43.60%	93	29.70%
		Very much	24	13.90%	15	10.70%	39	12.50%
		An extreme amount	11	6.40%	2	1.40%	13	4.20%
Environmental	To what extent do you have the opportunity for leisure activities?	**Not at all**	**15**	**8.70%**	**31**	**22.10%**	**46**	**14.70%**
		A little	**23**	**13.40%**	**42**	**30.00%**	**65**	**20.80%**
		A moderate amount	49	28.50%	49	35.00%	98	31.40%
		Very much	60	34.90%	18	12.90%	78	25.00%
		An extreme amount	25	14.50%	0	0.00%	25	8.00%
Environmental	How satisfied are you with the condition of your living place?	**Very dissatisfied**	**5**	**2.90%**	**6**	**4.30%**	**11**	**3.50%**
		Dissatisfied	**9**	**5.20%**	**32**	**23.20%**	**41**	**13.20%**
		Neither satisfied nor dissatisfied	**20**	**11.60%**	**49**	**35.50%**	**69**	**22.30%**
		Satisfied	98	57.00%	43	31.20%	141	45.50%
		Very satisfied	40	23.30%	8	5.80%	48	15.50%
Environmental	How satisfied are you with your access to health services	**Very dissatisfied**	**2**	**1.20%**	**6**	**4.30%**	**8**	**2.60%**
		Dissatisfied	**10**	**5.80%**	**26**	**18.70%**	**36**	**11.50%**
		Neither satisfied nor dissatisfied	22	12.70%	55	39.60%	77	24.70%
		Satisfied	108	62.40%	48	34.50%	156	50.00%
		Very satisfied	31	17.90%	4	2.90%	35	11.20%
Environmental	How satisfied are you with your access to transport?	**Very dissatisfied**	**4**	**2.30%**	**15**	**10.70%**	**19**	**6.10%**
		Dissatisfied	**18**	**10.50%**	**48**	**34.30%**	**66**	**21.20%**
		Neither satisfied nor dissatisfied	30	17.40%	47	33.60%	77	24.70%
		Satisfied	91	52.90%	26	18.60%	117	37.50%
		Very satisfied	29	16.90%	4	2.90%	33	10.60%

*Due to an administrative error, this question was not asked of the Oudtshoorn participants.

8.1.2 Total score

The scoring algorithm used to compute the domain scores is shown in the Appendices. The coding script changes items that are scored negatively to a positive value. Note that contrary to the WHODAS-2, the higher the WHOQOL-BREF score, the better the quality of life. The mean score was 49.8 (SD=9.57, range 23.3-76.5), see Figure 23.

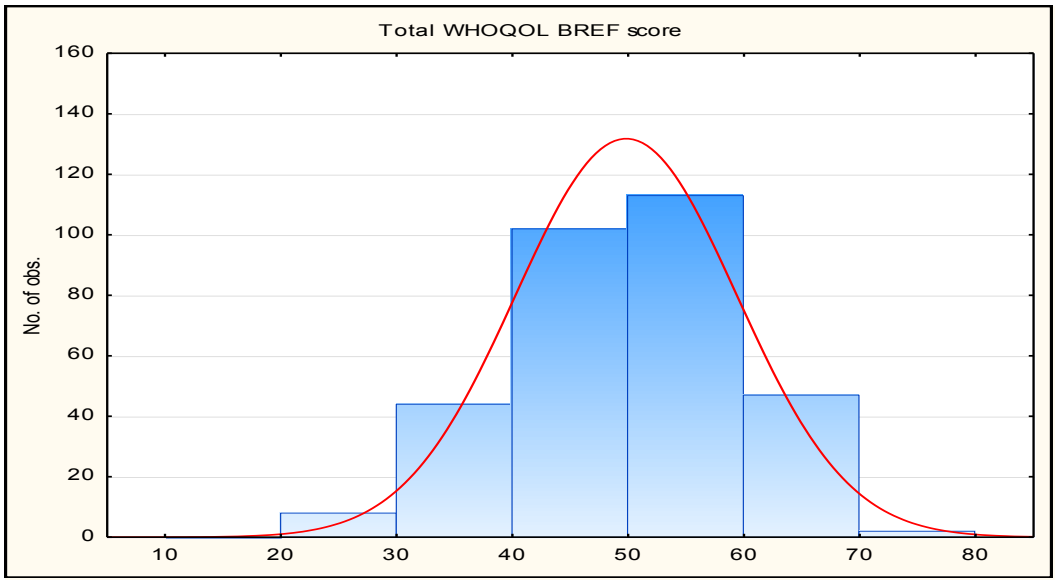


Figure 22: Histogram of the WHOQOL-BREF total scores (N=316)

8.1.3 Domain scores

The highest median score was for the Social domain that includes support from friends and personal relationships and the lowest was for the Physical domain that includes pain, mobility, sleep and energy (Table 27, Figure 24 and 25).

Table 27: Median score of each WHOQOL-BREF domain

	Valid N	Median	Minimum	Maximum
Physical	333	11.4	4.00	18.3
Psychological	332	12.7	5.33	20.0
Social	318	13.3	4.00	20.0
Environmental	332	12.5	4.50	20.0

Note that maximum score is 20.

Men scored significantly higher than women on the Physical domain (Z=-2.10, p=0.036), Figure 24.

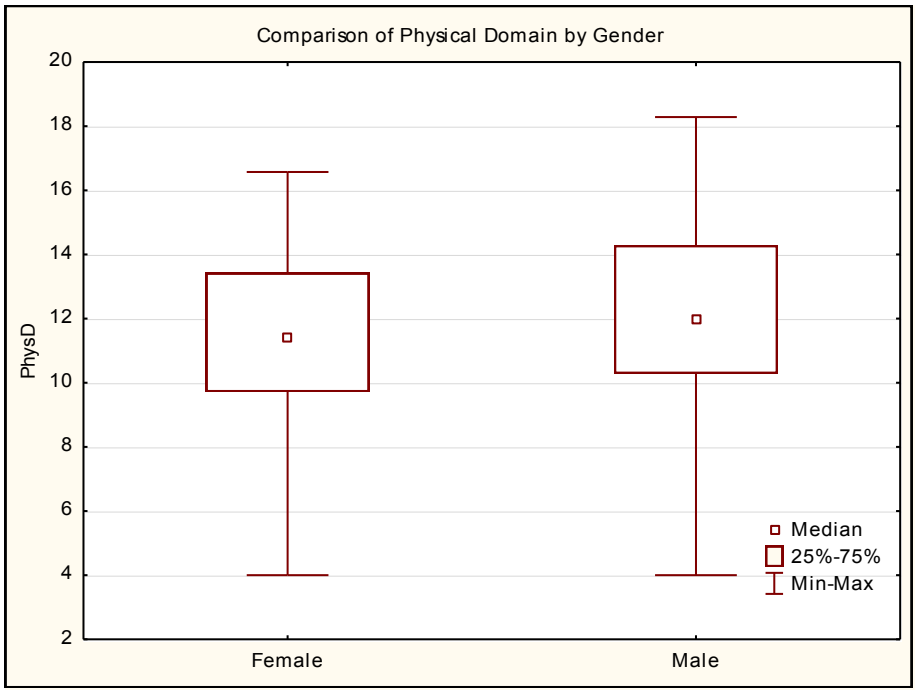


Figure 23: WHOQOL-BREF Physical domain score for women (N=180) and men (N=145)

A significant difference was seen in the average ranks of the domains (ANOVA Chi Sq. 122.4451; N=316, df=3, p<.001), where the Social domain was highest and the Physical domain lowest (Table 29).

Table 28: Rank scores across domains of the WHOQOL-BREF

	Average Rank	Sum of Ranks	Mean	Std.Dev.
Physical	1.91	604	11.6	2.69
Psychological	2.70	854	12.7	2.66
Social	2.98	942	13.3	3.43
Environmental	2.41	761	12.2	2.77

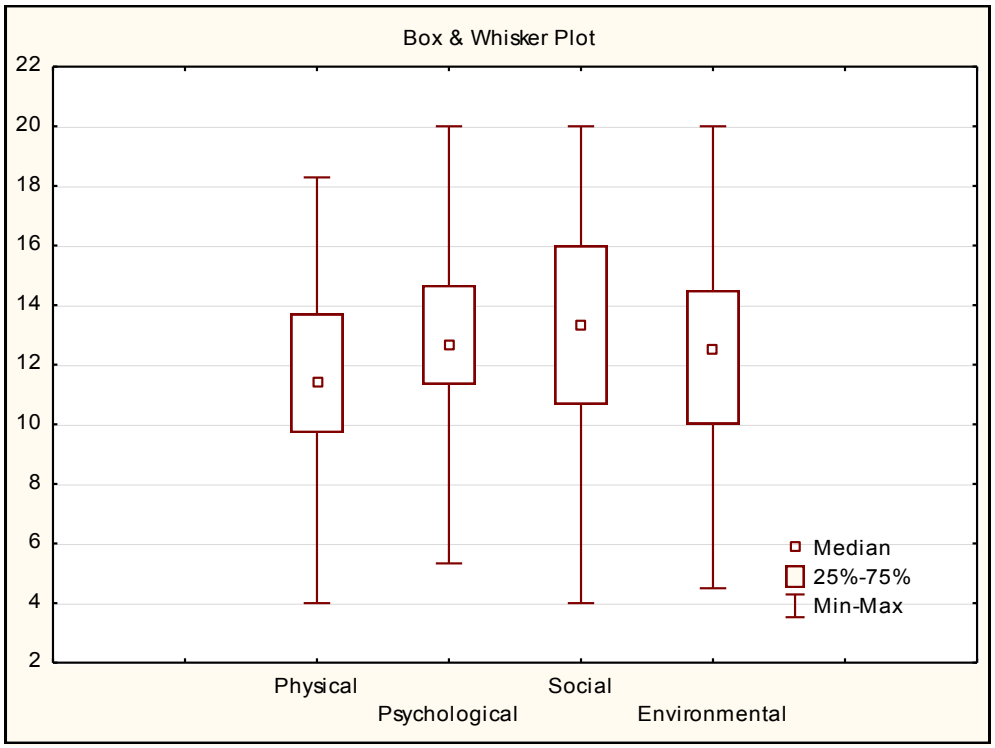


Figure 24: Median scores on the four WHOQOL-BREF domains (N=325)

Each domain was significantly correlated ($p<.05$) with the other three, with the highest rho between the Physical and Psychological domains and the lowest between the Social and Environmental domains (Table 29).

Table 29: Spearman's correlation between the four domains of the WHOQOL-BREF (N=325)

	Physical	Psychological	Social	Environmental
Physical	1.00	0.72	0.53	0.64
Psychological	0.72	1.00	0.58	0.61
Social	0.53	0.58	1.00	0.48
Environmental	0.64	0.61	0.48	1.00

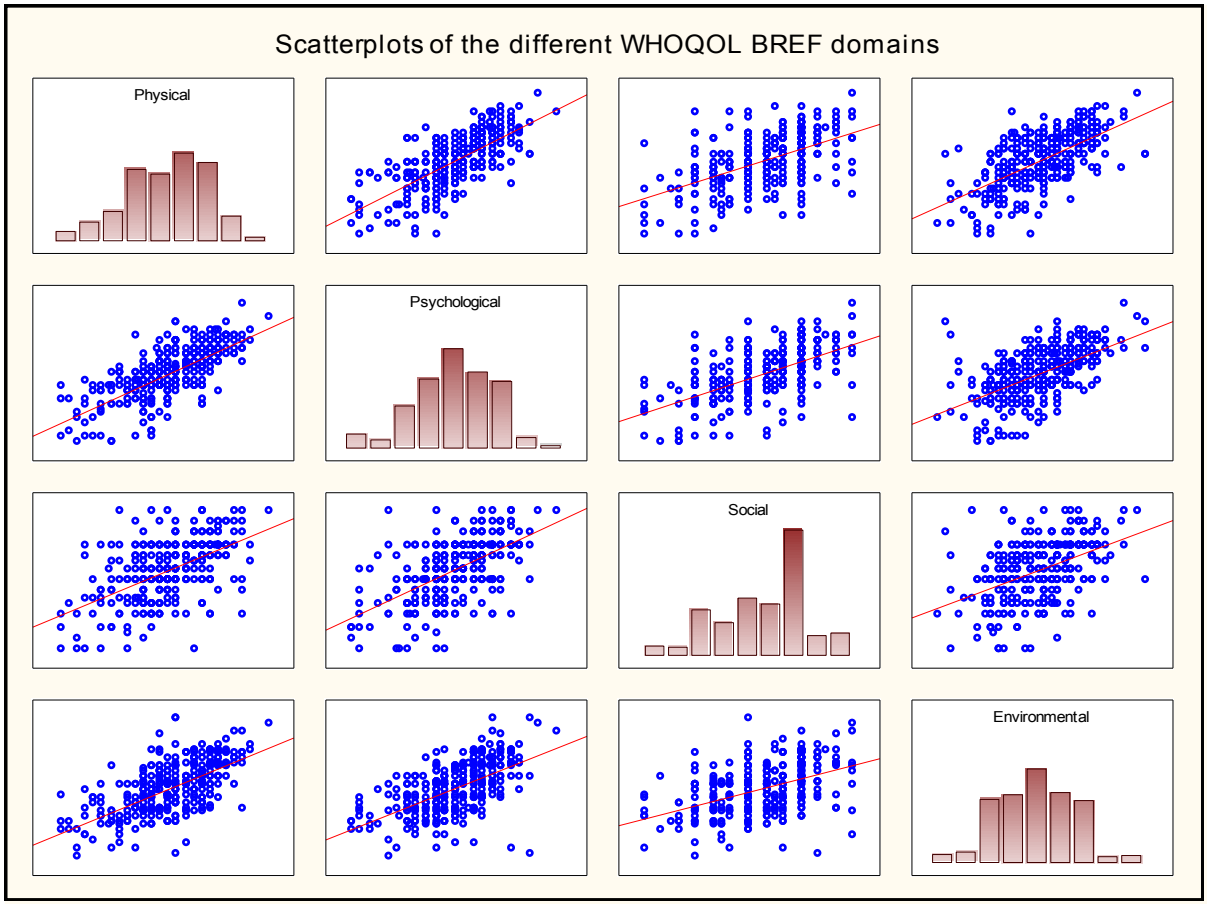


Figure 25: Scatterplots of the four domains scores of the WHOQOL-BREF

8.2 Comparison between the two sites

Oudtshoorn participants had a significantly higher (better) mean score (7%) than Nyanga respondents, as shown in Table 30.

Table 30: Mean and median WHOQOL-BREF scores by site

	Oudtshoorn			Nyanga				
	N	Mean	SD	N	Mean	SD	t-value	
Total score	171	53.11	8.7	145	45.96	9.03	-7.1*	p<0.001
Domain		Median	Range		Median	Range	Z adj	
Physical	173	12	5.7-18.3	160	10.9	4-16.6	5.69	p<0.001
Psychological	173	13.3	6-20	159	12.7	5.3-18	2.89	0.004
Social	173	14.0	4-20	145	13.3	4-20	2.47	0.013
Environmental	172	13.5	8.5-20	160	10.5	4.5-16	10.92	p<0.001

* df=314

The median score was highest in the Social domain for both sites, but there were many more missing responses because this domain included the question related to sexual activity. The median score per domain was significantly higher in Oudtshoorn in every case and the largest difference was seen in the Environmental domain (Figure 27).

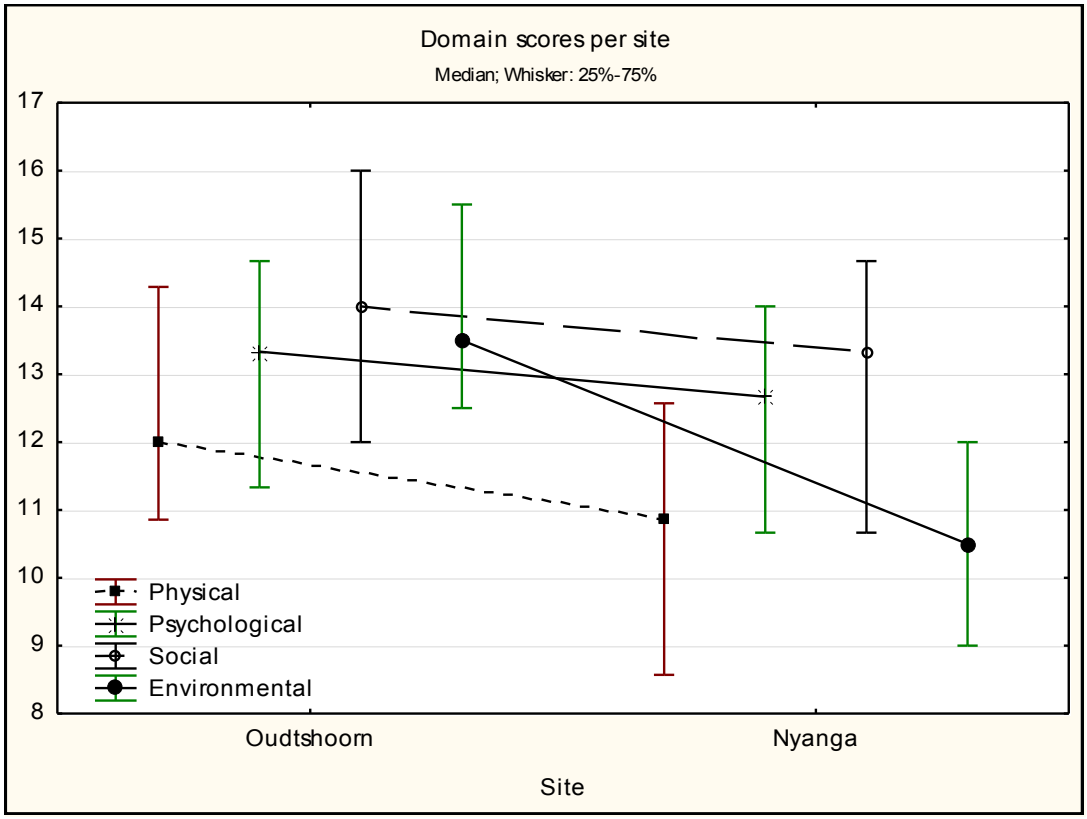


Figure 26: Median WHOQOL-BREF domain scores by site

The specific items that resulted in these differences are depicted inFigure 261. Nyanga respondents had a higher frequency of problems for each question, apart from the questions on need for medical treatment, sleep, support from friends and access to information, where the difference was 10% or greater.

The Environmental scores indicated that the Nyanga context presented more barriers, with some items having a 30% higher frequency of problems (access to money, leisure activities and transport). There was little difference between the sites with regard to safety in everyday life, with 20-30% in each site reporting that they did not feel safe in their daily life.

Table 31: Frequency of respondents reporting problems for each question ("moderate" responses included as a problem, but neutral responses were excluded)

	Oudtshoorn N=175		Nyanga N=141		% difference
1. How would you rate your quality of life?	35	20.0%	62	44.3%	24.3%
2. How satisfied are you with your health? *			28	20.0%	20.0%
Physical domain					
3. To what extent do you feel that (physical) pain prevents you from doing what you need to do?	49	28.2%	59	32.2%	4.0%
4. How much do you need any medical treatment to function in your daily life?	67	38.5%	19	13.7%	-24.8%
5. Do you have enough energy for everyday life?	11	6.6%	43	30.7%	24.1%
6. How well are you able to get around?	75	43.4%	68	49.3%	5.9%
7. How satisfied are you with your sleep?	54	31.2%	30	21.4%	-9.8%
8. How satisfied are you with your ability to perform your daily living activities?	47	27.0%	65	46.8%	19.8%
9. How satisfied are you with your capacity for work?	64	37.0%	75	53.5%	16.5%
Psychological domain					
10. How much do you enjoy life?	45	25.7%	41	30.1%	4.4%
11. To what extent do your feel your life to be meaningful?	19	11.1%	20	14.4%	3.3%
12. How well are you able to concentrate?	16	9.2%	32	23.0%	13.8%
13. How satisfied are you with yourself?	80	46.5%	60	42.8%	-3.7%
14. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	93	53.7%	72	51.8%	-1.9%
Social domain					
15. How satisfied are you with your personal relationships?	49	28.3%	32	25.4%	-2.9%
16. How satisfied are you with your sex life?	22	12.7%	30	31.3%	18.6%
17. How satisfied are you with the support you get from your friends?	31	23.5%	14	10.2%	-13.3%
Environmental domain					
18. How safe do you feel in your daily life?	40	22.9%	42	30.2%	7.3%
19. How healthy is your physical environment?	20	11.4%	31	22.1%	10.7%
20. Have you enough money to meet your needs?	31	27.9%	114	82.0%	54.1%
21. How available to you is the information that you need in your day-to-day life?	106	61.3%	62	44.2%	-17.1%
22. To what extent do you have the opportunity for leisure	38	22.1%	73	52.1%	30.0%

activities?					
23. How satisfied are you with the condition of your living place?	14	8.1%	38	27.5%	19.4%
24. How satisfied are you with your access to health services?	12	7.0%	32	23.0%	16.0%
25. How satisfied are you with your access to transport?	22	12.8%	63	45.0%	32.2%

*Due to an administrative error, this question was not asked of the Oudtshoorn participants.

8.3 EQ-5D

The EQ-5D-3L measures HRQoL across five domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. A three-point scale with no problems, some problems and extreme problems is used. There were 320 responses to the EQ-5D and the mean score was 54.6 (SD=22.6, Range=0-100). Those identified with severe disability (refer to Chapter 5) tended to rate their HRQoL lower than those who reported some disability (Figure 28).

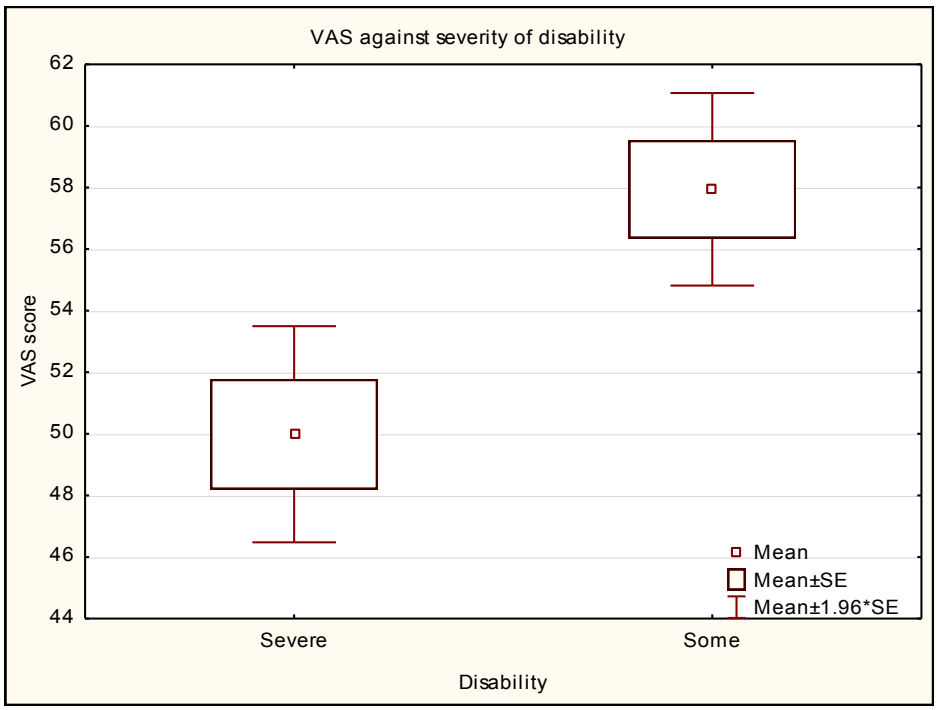


Figure 27: EQ-5D VAS score according to severity of disability

Participants in Oudtshoorn reported fewer problems than those in Nyanga. Most problems were perceived in the domains of Pain/Discomfort (74%) and Anxiety/Depression (72%) for the Nyanga sample (Table 32). The domains affecting the Oudtshoorn sample most were Usual Activities (52%) and Pain/Discomfort (50.8%).

Table 32: Health-related quality of life for people with disabilities based on EQ-5D-3L

	Mobility		Self Care		Usual Activities		Pain/Discomfort		Anxiety/depression	
	N	%	N	%	N	%	N	%	N	%
OUDTSHOORN (n=189)										
No problem	75	39.5	122	64.2	91	47.9	93	49.2	126	66.3
Some problem	104	54.7	40	21.1	65	34.2	58	30.7	49	25.8
Extreme	10	5.3	28	14.7	34	17.9	38	20.1	14	7.4
Missing	1	0.5	0.0	0.0	0.0	0.0	0	0.0	1	0.5
Total	*189*	*100*	*190*	*100*	*190*	*100*	*189*	*100*	*190*	*100*
NYANGA (n=165)										
No problem	58	35.2	104	63.0	54	32.7	39	23.6	44	26.7
Some problem	92	55.8	44	26.7	73	44.2	82	49.7	83	50.3
Extreme	13	7.8	15	9.1	34	20.6	41	24.8	36	21.8
Missing	2	1.2	2	1.2	4	2.5	3	1.9	2	1.2
Total	*165*	*100*	*163*	*100*	*165*	*100*	*165*	*100*	*165*	*100*

8.3.1 Index Score across sites

Oudtshoorn EQ-5D index scores were significantly higher (0.59, SD=0.39) than Nyanga scores (0.34, SD=0.42, t=-5.8, p<.001). This gave 4.1 (1-.59*10) Healthy Years of Life Lost per 10 years in the Oudtshoorn group and 6.9 (1-.34*10) HYLL in the Nyanga group.

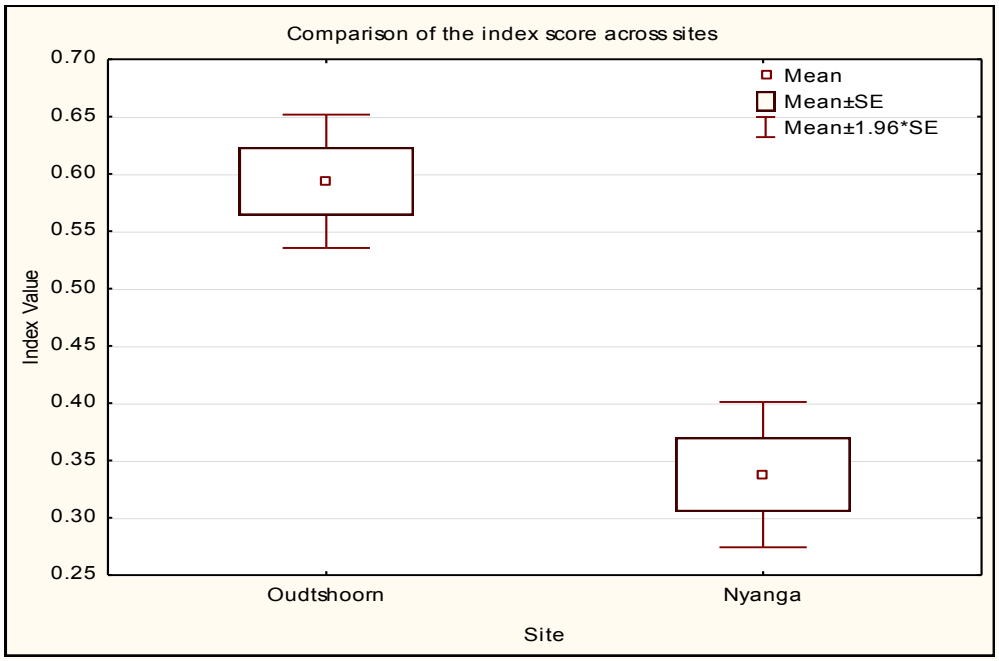


Figure 28: EQ-5D index scores by site (Oudtshoorn N=189, Nyanga N=165)

Oudtshoorn presents a much higher index score than Nyanga, thus suggesting a much better perceived HRQoL. The Index score of Nyanga being much lower than 0.5 (Figure 28)

The index score across health conditions has been presented in Table 18 and discussed in Chapter 6.

8.3.2 VAS Scores across sites

The VAS reflects the individual's own perception of their health state. There were several missing values for this variable, particularly from Oudtshoorn with only 156 out of a possible 189 responses. The overall mean VAS score was 54.8 with a large SD=22.8. The Oudtshoorn respondents reported a HRQoL more than 10% higher than the Nyanga group and this was significantly different (Figure 30). The Oudtshoorn values were approximately normally distributed around the mean of 60, but the Nyanga scores spiked between 30 and 50.

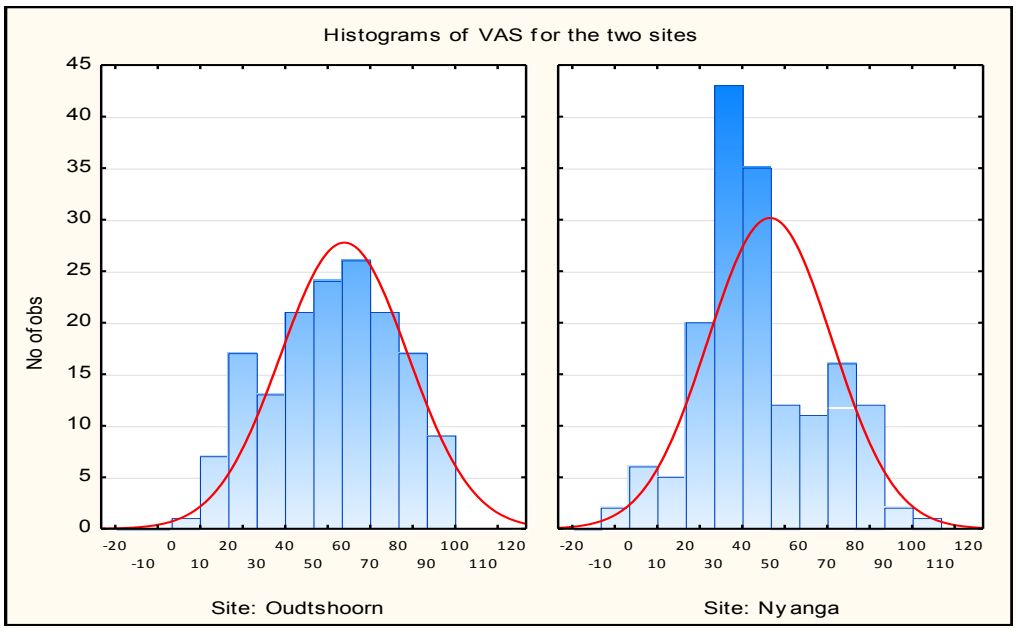


Figure 29: Mean EQ-5D VAS scores by site (Oudtshoorn N=156, Nyanga N=165)

There was a significant difference in the mean EQ-5D VAS scores between the two areas Oudtshoorn 61.0 and Nyanga 49.5 (SD 22.4 P<0.001). There were significant positive but somewhat weak correlations between the VAS and the Index scores, (p<0.001), with Oudtshoorn showing a weaker correlation (r=0.461) compared to Nyanga (r=0.569), (see Figure 31 and Figure 32).

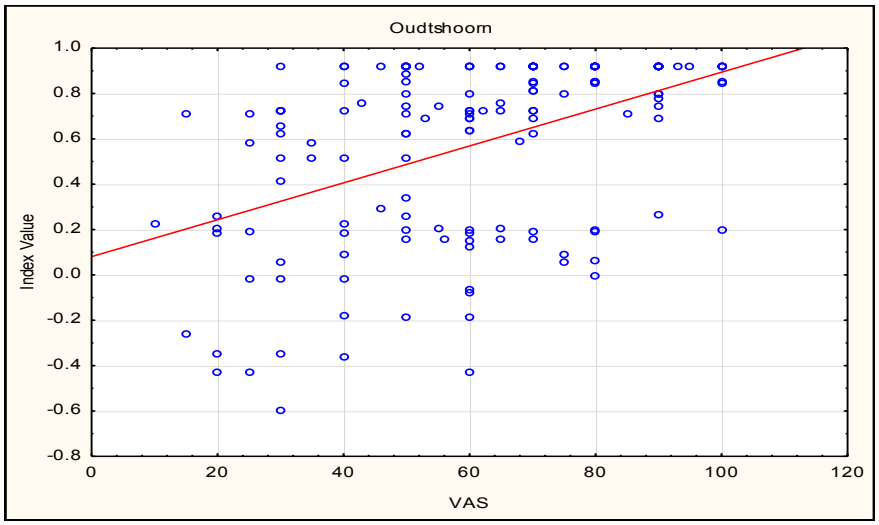


Figure 30: Correlation between mean EQ-5D VAS and index scores in Oudtshoorn (N=156)

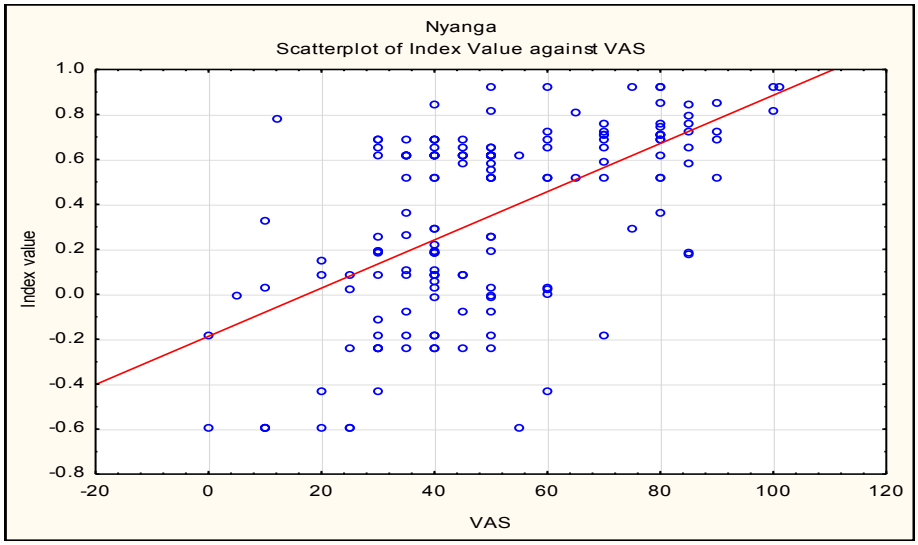


Figure 31: Correlation between mean EQ-5D VAS and index scores in Nyanga (N=165)

8.4 Determinants of QoL/HRQoL

Bivariate analysis was done to establish which factors should be included in multivariate analysis. Age was not correlated with either the WHOQOL-BREF total score or the VAS (Figure 32 and Figure 34).

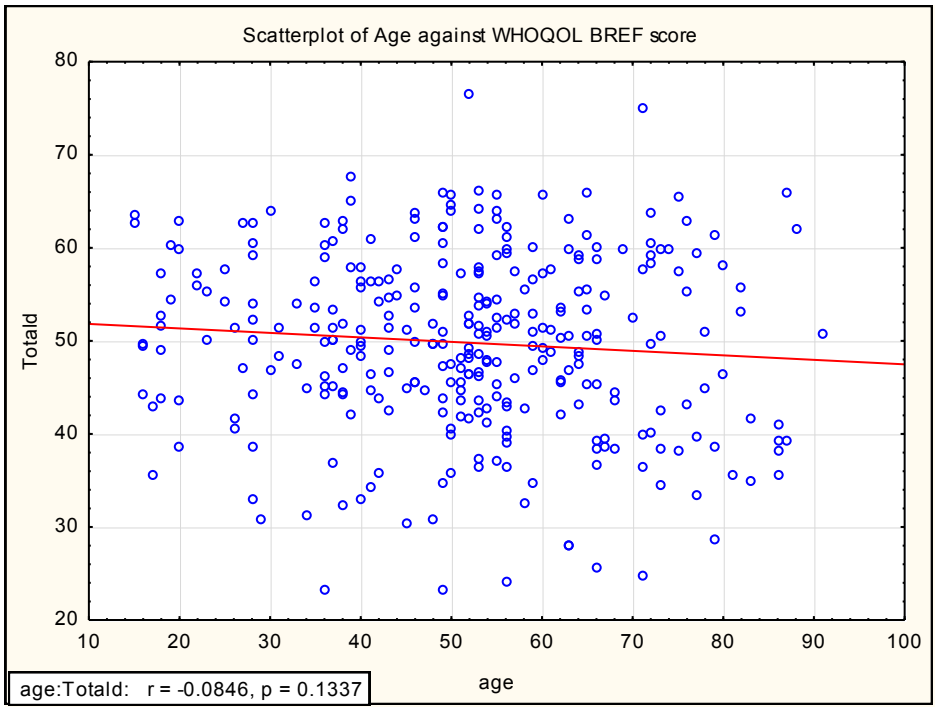


Figure 32: Scatterplot of age and WHOQOL-BREF scores (N=315)

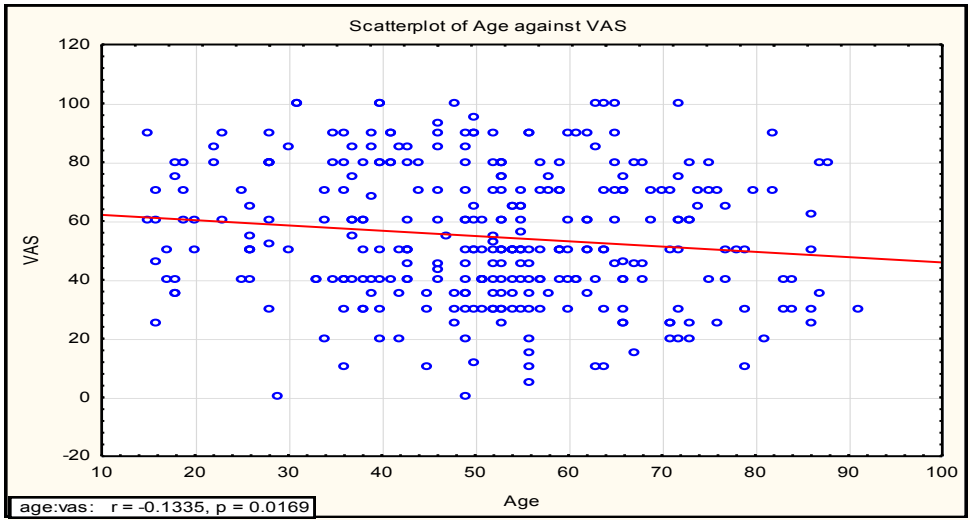


Figure 33: Scatterplot of age and EQ-5D VAS score (N=320)

Bivariate analysis indicated that the EQ-5D VAS and index score and the WHOQOL-BREF scores were significantly different between sites and by employment status (Table 33). The WHOQOL-BREF score was also higher for people married or cohabitating. There were was no differences in scores for the other demographic variables and these were thus not included in the regression models.

Table 33: Quality of life scores by site, gender, marital and employment status

	Mean	Std.Dev.	N	Mean	Std.Dev.	N	t-value	df	p
Site	**Oudtshoorn**			**Nyanga**					
VAS	60.4	49.1	156	21.5	22.4	164	-4.6	318	***p<.001***
Index score	0.6	0.3	175	0.4	0.4	166	-5.8	339	***p<.001***
WHOQOL Total	53.1	46.0	171	9.0	8.8	145	-7.1	314	***p<.001***
Gender	**Female**			**Male**					
VAS	54.5	22.6	167	55.5	23.1	144	-0.38	309	0.702
Index score	0.4	0.4	181	0.5	0.4	149	-0.68	328	0.503
WHOQOL Total	49.5	9.7	173	50.3	9.5	134	-0.70	305	0.48
Marital status	**Not-married**			**Married**					
VAS	53.1	22.8	228	58.5	21.8	92	-2.0	318	0.054
Index score	0.5	0.4	240	0.5	0.4	101	-0.8	339	0.410
WHOQOL Total	48.8	9.5	217	52.2	9.3	99	-3.0	314	***p<.001***
Education*	**Three years or less schooling**			**Four years or more schooling**					
	51.10	27.27	31	56.54	21.92	228	1.566	257	0.119
	0.35	0.54	34	0.51	0.39	241	1.720	38.1	0.093
	49.58	9.20	33	50.86	9.11	227	0.753	258	0.452
Employment status	**Not employed**			**Employed**					
VAS	52.7	22.0	287	71.8	21.4	33	-4.7	318	***p<.001***
Index score	0.4	0.4	306	0.7	0.3	35	-3.2	339	***p<.001***
WHOQOL Total	49.3	9.4	281	54.2	10.0	35	-2.9	314	***p<.001***

*Calculated with separate variances.

As the VAS is a global measure of HRQoL, it was chosen as the dependant measure to explore the contribution of the different factors to HRQoL. The variables that contributed to VAS were then examined using multiple regression analysis. Once three outliers had been removed, the model that included the five EQ-5D domains, site and employment accounted for 39% of the variance (Table 34). Employment, mobility, pain/discomfort and anxiety/depression significantly reduced the VAS score.

Table 34: Predictors of the EQ-5D VAS score (N=318)

	b	Std.Err. of b	t(309)	p-value
Intercept	71.7	1.930	37.16	***P<0.001***
Site (Nyanga)	2.4	2.306	1.05	0.292
Employed	10.0	3.332	3.00	***0.003***
Mobility	-5.6	2.174	-2.59	***0.010***
Self-care	-1.7	2.124	-0.82	0.414
Usual activities	-2.0	2.132	-0.94	0.350
Pain/discomfort	-4.0	1.776	-2.24	***0.026***
Anxiety/depression	-12.0	1.738	-6.90	***P<0.001***

Adjusted r^2=0.39

8.5 Summary of Results

The total WHOQOL-BREF score had a mean value of 50 that was not associated with gender or age. The respondents were most satisfied with the items in the Social domain whereas the Physical domain had the lowest score. All four WHOQOL-BREF domains were significantly correlated with each other, where the Social domain had the lowest and the Physical domain the highest correlations. Oudtshoorn residents had fewer problems than Nyanga residents for most of the domains, with the exception of access to information and support from friends. There was no difference in the perception of personal safety between the two sites.

As expected from the individual item analysis, Oudtshoorn respondents scored higher in every domain. The largest difference in median score (3) was in the Environmental domain.

With regard to the EQ-5D, most problems were perceived in the domains of Pain/Discomfort (74%) and Anxiety/Depression (72%) for the Nyanga sample. The domains mostly affecting the Oudtshoorn sample were Usual Activities (52%) and Pain/Discomfort (50.8%).

The Oudtshoorn sample again reported fewer problems in every domain and this was reflected in a significantly higher EQ-5D index score. The mean VAS was 54.6% and as more than half of the Nyanga respondents scored between 20 and 50, their score was 10% less than the Oudtshoorn residents. The index and VAS scores were correlated, but the fit was better in Nyanga. Multiple regression analysis indicated that if all the other domains were equal, site did not reduce the VAS. However, being employed raised the VAS by ten points, whereas having problems with Mobility, Pain/Discomfort or Anxiety/Depression lowered it significantly. The coefficient for Anxiety/Depression was -12 for each level; this implies that the score of someone who was very anxious or depressed would be 24% lower.

Significant differences in QOL scores were noted between site and whether you were employed or not.

8.6 Discussion

The results of the HRQoL analysis reflect the findings reported in the chapter on functional limitations (Chapter 7) in that the Oudtshoorn respondents reported better quality of life in every respect. There were some unexpected findings, however, particularly with regard to the determinants of the perceived global HRQoL as measured by the VAS.

8.6.1 WHOQOL-BREF

The overall WHOQOL-BREF score of 49.8 (SD 9.57) was similar to that obtained in other studies focusing on the elderly in urban and rural areas [147, 304], although the results for individual domains differed. A study, which administered the WHOQOL-BREF to adult community residents in a major metropolitan city in southern China, for example, reported that approximately 16% of respondents had problems in the domains of Energy, Concentration and Body image, compared to the 5.5-14.2% in the current study. The South African population had more problems on Sexual activity, (14.2% compared to 5% in the Chinese group [305], although there were a large number of missing responses to this question. It is unclear why there is such a discrepancy.

As discussed in Chapter 10, the WHOQOL-BREF domains do not have very high internal consistency and the four-domain structure is not supported by factor analysis. On examination of the questions, it is becomes apparent why this is so. For example, respondents in both areas were dissatisfied with their functioning on the Physical domain, which is consistent with the functional limitations discussed in earlier chapters. However, this domain includes sleep and energy as well as self-care and life activities such as capacity for work. It is not surprising that

this domain should be correlated with the others, as there is some overlap between the domains. The phrasing of the questions may be difficult to understand for respondents with only primary school education.

The Oudtshoorn respondents reported a greater need for medical treatment, possibly reflecting the number of older respondents and the relatively greater number of those with non-communicable diseases and severe disability requiring care.

The biggest discrepancy between the two areas was with regard to the Environmental domain. Surprisingly, safety did not emerge as being very different between the two sites, although the assumption that the urban site is a more dangerous place to live was borne out by the greater burden due to Intentional trauma reported in Chapter 6. Another question that resulted in counterintuitive results was related to having money to meet needs. The fact that 20% of the Oudtshoorn sample reported “An extreme amount” could indicate that this question was not well understood.

Regardless of the overall queries regarding validity, some items revealed new data. An area of concern raised by more than 50% of the respondents in both areas was related to access to information. Interventions proposed to address the gap in access to information between people with and without disabilities include improved access to technology such as the Internet [306, 307]. Very few people with disability have access to a computer, possibly due to lack of financial resources or inability to get to public places with free internet [308]. It is therefore recommended that free public Internet be made universally accessible or that computers be considered an official assistive device. An assumption would be that very few of our respondents owned a computer, however, most could not access a library similarly due to walking difficulties. This study also found that over 40-50% of people with disabilities living in the urban area were dissatisfied with leisure activities and transport, indicating that these may be reasons why the Participation domain score was much lower in Nyanga.

In general, the WHOQOL-BREF did not add very much information to that already learned from the WHODAS-2. In addition, it did not appear to be as robust as the WHODAS-2. Thus, it may be preferable to use the WHODAS-2 to examine functioning, and the EQ-5D to monitor HRQoL in future surveys. However, this suggestion would leave a gap with respect to the gathering of environmental factors.

8.6.2 The EQ-5D

The responses to the EQ-5D domains were similar to other studies in under-resourced areas in Cape Town [309, 310] and elsewhere, in that Self-care was the least affected domain and Pain/discomfort and Anxiety/depression were the most affected [311]. As expected, the Oudtshoorn residents had a much higher index score, caused in part by more problems with Usual Activities, Pain/discomfort and Anxiety/depression. The lower index scores (which translate into poorer QoL and more healthy life years lost) were discussed in Chapter 6 as they were used to calculate the burden due to underlying causes of disability.

The mean VAS score of 55% was considerably less than that reported in a similar population in Cape Town (80.1, SD=20.4) from 2003. Although the study was done some time ago, and before the economic recession [311], the presence of disability appears to severely reduce HRQoL.

8.6.3 Determinants of HRQoL

It is evident that many factors impact on the perception of quality of life, and the determinants of HRQoL and QoL are an ongoing topic of research. Being female [147, 312, 313], older, of poor socio-economic status, having no formal education, being unemployed and not married were significantly related to poorer quality of life [147, 168-170]. Women have lower perceived quality of life compared to men. Studies focusing on the elderly in South Africa show that the health care system is not equipped to deal with the needs, subjective well-being or associated rise of chronic conditions among the elderly [314, 315] . Another study reported that respondents living in rural areas tend to rate their QoL lower than those in urban areas [147]. In the current study, however, those with higher socio-economic status and better income reported lower HRQoL, which is inconsistent with previous studies [315, 316].

Although the results across the instruments suggest that living in Nyanga is associated with a poorer HRQoL, the regression analysis did not show site as being predictive of HRQoL once the other factors were included. What could be an explanation for this result, which seems to contradict both published studies and other findings in the current study? The importance of using multiple regression analysis is highlighted by these findings. Although individual factors might be associated with a reduced VAS score, once all the factors interact with each in the chosen model it becomes apparent that the poorer HRQoL reported by those in Nyanga is in fact mediated by their poorer functional abilities, as measured by the EQ-5D domains. This implies that, although living in an under-resourced urban area might be associated with poorer functional ability, the perception of a poor global HRQoL is not due to the living situation but due to the functional limitations associated with it and with employment status. It is clear from

Chapter 6 that the urban population bears a larger burden of disability and it is this burden, rather than their geographic location, that leads them to report a worse HRQoL. In particular, the presence of Anxiety/depression leads to a large decrease in VAS score, where those with severe anxiety and depression were predicted to have a 24% decrease, and over 70% of Nyanga residents report problems in this area compared to 33% in Oudtshoorn. This finding is consistent with the high prevalence of mental health problems in the Nyanga sample reported in previous chapters, if problems with concentration can be taken as a proxy for mental health difficulties.

8.6.4 Implications for service delivery

The HRQoL of the respondents in both areas was poor and the results indicate that they need medical and social support. People with disabilities are in urgent need of mental and emotional support, as evidenced by their high levels of anxiety and depression which were picked up by both instruments. This was particular so in Nyanga, but the WHOQOL-BREF did identify a similar problem in the Psychological domain for the Oudtshoorn residents. As mood had the greatest impact on self-perceived HRQoL, this area should be prioritised.

The low Physical domain scores highlight the need for functional re-education related to pain management and mobility, as identified by the WHODAS-2. Environmental aspects such as access to transport and information have not been adequately addressed and the roll-out of Internet access and transport should be expedited, with special attention to accessibility for people with disabilities. Finally, employment was the largest contributor to improved HRQoL. The small number of employed participants and the low educational level of many people with disability point to a need for vocational training and further assistance in finding suitable employment.

9 Environmental Barriers and Access to Services: Results and Discussion

The barriers most frequently identified by people with disabilities in both areas were Transport, the Natural Environment and Help in the Home (Table 35). More respondents in Nyanga (50%) than Oudtshoorn (21%) thought Help in the Home was a big barrier. The biggest problem for Nyanga residents was Prejudice and discrimination.

Table 35: Environmental barriers experienced by people with disabilities

Domain	Oudtshoorn (N=196)			NYANGA (N=183)		
	Small Problem (%)	Big Problem (%)	Total	Small Problem (%)	Big Problem (%)	Total
Transport	40.3	19.9	60.2	46.3	25. 8	72.1
Natural environment	43.5	18.9	62.4	49.7	22.5	72.5
Surroundings	31.4	24.1	55.5	36.5	34.0	70.5
Health care services availability	24.1	11.5	35.6	23.1	45.2	68.3
Help in home	24.6	22.0	46.6	21.5	50.3	71.8
Attitudes at school or work	13.6	6.8	20.4	11.6	15.5	27.1
Prejudice and discrimination	15.7	14.1	29.8	26.2	48.1	74.3

9.1 Access to Services

People with disabilities were asked to identify any services they needed from a list provided, and to indicate whether they had received those services. Health and welfare services and medical rehabilitation were the three most common services identified. Most respondents in both areas were able to receive the health and welfare services that they needed, but the services related specifically to those with disabilities were not adequately accessed. Only 56% of those who needed rehabilitation services received it in Oudtshoorn and 65% in Nyanga. Most people with disabilities who needed home-based care services in Oudtshoorn (67%) and Nyanga (60%) did not receive it (Table 36).

Table 36: Services needed and received by people with disabilities in Oudtshoorn (n=181) and Nyanga (n=178), missing=20

Services Needed	Received Oudtshoorn	Did not receive Oudtshoorn	Total Needed Oudtshoorn	Received Nyanga	Did not receive Nyanga	Total Needed Nyanga	Chi-sq
Home-based care	10 (33.3%)	20 (66.7%)	30 (16.6%)	26 (40%)	35 (60%)	61 (34.3%)	NS
Disability Counselling	19 (46.3%)	22 (53.7%)	41 (22.7%)	78 (66.7%)	39 (33.3%)	117(65.7%)	5.3, p=0.021
Vocational training	10 (50.0%)	10 (50%)	20 (11%)	16 (18.8%)	69 (81.2%)	85 (47.8%)	8.5, p=0,004
Medical rehabilitation	53 (55.8%)	42 (44.2%)	95 (52.5%)	83 (64.8%)	45 (35.2%)	128(71.9%)	NS
Educational services	16 (57.1%)	12 (42.9%)	28 (15.5%)	43 (53.1%)	38 (46.9%)	81 (45.5%)	NS
Assistive devices	51 (63.0%)	30 (44.8%)	81 (44.8%)	60 (56.1%)	47 (43.9%)	107 (60%)	NS
Welfare service	84 (80.8%)	20 (19.2%)	104 (57.5%)	102 (77.3%)	30 (22.7%)	132 (74.2%)	NS
Health service	133 (99.0%)	1 (1%)	134 (74%)	111 (84.1%)	21 (15.9%)	132 (74.2%)	20.15 p<.001

Of those who reported being in need of services, the largest percentage with unmet needs were for medical rehabilitation (42%), assistive devices (44%) and home-based care (59%). In contrast, 17% reported being in need of medical care but had not received it.

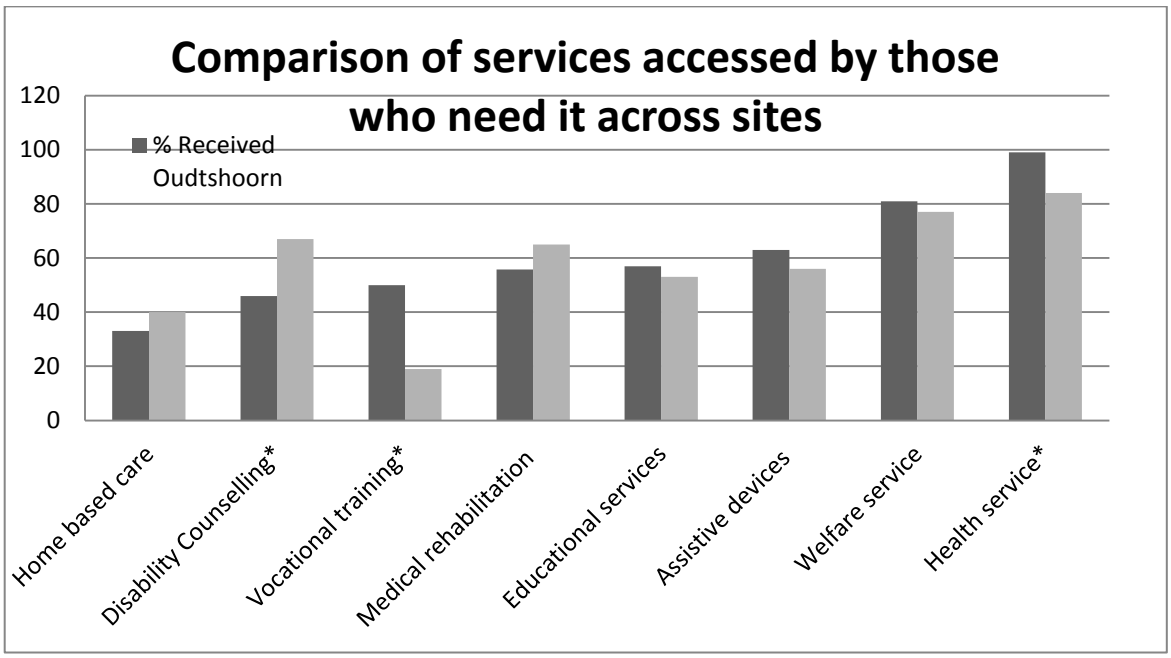


Figure 34: Comparison of services accessed by those who need it across sites.

*Indicates significant difference in proportion.

There were significant differences between the two sites in those who needed and received disability counselling (p=0.021), vocational training (p=0.004) and health services (p<.001) (Figure 34).

Access to medical rehabilitation was of particular interest for this study, and was thus chosen as the variable to discriminate between those able to access care and those in need who had not had intervention. A smaller proportion of men who needed rehabilitation had accessed it (Table 37) Those over 65 years old were less able to access services, with more than 50% not having received the services that they needed (Chi-sq.=5.9, p=0.015)(Table 38). There were no differences according to income categories.

Table 37: Gender and access to medical rehabilitation of those that required it

Gender	Not receiving medical rehabilitation	%	Receiving medical rehabilitation	%	Total
Male	51	58.6	60	44.1	111
Female	36	41.4	76	55.9	112
Totals	87		136		223

Chi-sq.=4.46, df=1, p=0.035

Table 38: Age and access to medical rehabilitation of those that required it

Age Category	No Rehabilitation	%	Rehabilitation	%	
Adult	31	30.0	72	70.0	103
Elderly	14		11	44.0	25
Totals	45		83		128

Chi-sq.=5.9, p=0.015

Respondents who needed medical rehabilitation services but had not received them had significantly worse QOL on the WHOQOL-BREF than those who had received the services (Table 39). This was especially seen on the Psychological and Social domains (and the Physical domain approached significance). There was no significant difference for the Environmental domain (Table 39).

Table 39: Access to medical rehabilitation according to mean WHOQOL-BREF domain score (N=217 who needed medical rehabilitation, 6 incomplete WHOQOL-BREF)

	Did not receive	SD	Received	SD	Df	p	Did not receive N	Received N
Physical	10.7	2.9	11.4	2.6	215	0.062	86	131
Psychological	11.8	2.6	12.7	2.6	214	0.015	85	131
Social	12.0	3.8	13.3	3.3	206	0.009	81	127
Environmental	11.6	2.6	11.7	2.8	215	0.848	86	131
Total	45.9	9.8	49.3	9.1	206	0.011	81	127

Responses to satisfaction with mode of transportation and access to health services were dichotomised into satisfied and dissatisfied (those who were indifferent were excluded). Satisfaction with transportation was associated with not needing medical rehabilitation services (Chi Sq.=7.42, df=2, p=0.024).

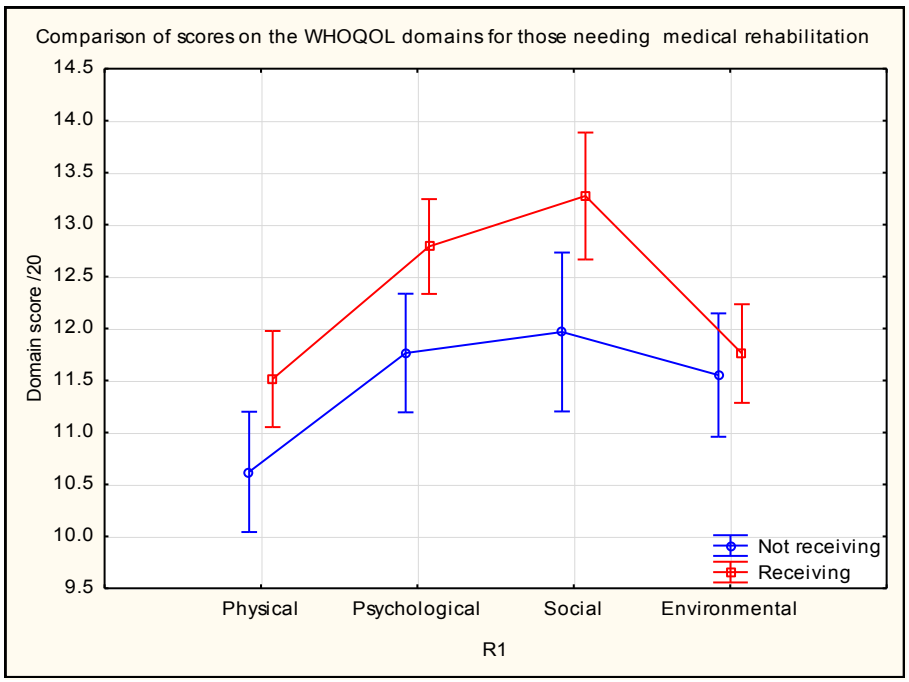


Figure 35: Comparison of WHOQOL-BREF scores for those needing medical rehabilitation

9.2 Summary of Results

People with disabilities living in Oudtshoorn perceived most barriers in the areas of transport and the natural environment. Health and welfare services were received by 99% and 80%, respectively, of those who needed them. Of those needing medical rehabilitation services, 53% did not receive them, while home-based care services were not received by 67% of those needing them. Of those living in Nyanga, 48% identified prejudice and discrimination as a big problem. Most people with disabilities were able to access the health and welfare services needed in Nyanga, but 81% and 60%, respectively, had not received the vocational training and home-based care they needed. The elderly were more likely not to have access to services. Receiving medical rehabilitation had a positive effect on QoL.

9.3 Discussion

It is well known that a formidable gap exists between the needs of, and the services available to, people with disabilities in resource-constrained settings [1]. The unavailability, inaccessibility and ignorance of services, combined with other socio-demographic variables, are some of the factors contributing to this gap. These factors are further compounded by under-reported data on the number of people with disability and the severity of impairment. These are all factors that impede a co-ordinated plan for service delivery, especially in resource-constrained settings where services are mostly fragmented. People with disabilities experience exclusion from society, which impacts on their level of awareness for services that could be beneficial to them [317]. The results of the study support this, in that only mainstream services such as health and welfare were accessed by those who needed it. People with disabilities appear to have difficulty accessing other medical services, particularly in the area of rehabilitation and counselling. There is a large unmet need for rehabilitation services and assistive devices, in that approximately one-third of the respondents reported that they needed services but had not accessed them. This was in contrast to general health services that had been consulted by all but 18%. The reason for this discrepancy may be the large number of community health clinics in the area under study, however few of them have rehabilitation personnel and those with disabilities might have found it difficult to attend clinics if they were not in the near vicinity.

A worrying finding was that over half of the participants over 65 years of age had not accessed services. The elderly represent a particularly vulnerable group and should be targeted in any attempt to expand services. However, it does not appear as if the cause of disability is associated with access, as 40-50% of those whose disability was caused by trauma,

maternal/child health factors or chronic diseases of lifestyle had not accessed services. More of those with infectious diseases had accessed services.

Surprisingly, the environmental components were not related to functional limitations. It may be that in such a severely resource-constrained situation, individuals with and without disability are dissatisfied with the available transport and environmental factors in general. Particular questions relating to the environment do not discriminate between respondents. However, more of those requiring rehabilitation reported dissatisfaction with their transport options. There is a system of designated transport for those with disabilities in the Cape Town Metropolitan area (Dial-a-Ride), but again, the participants do not seem to access the existing service, possibly due to financial constraints or lack of awareness.

Those who had not accessed medical rehabilitation services had the worst scores on the physical and psychological domains of the WHOQOL. However, a descriptive study such as this is unable to establish causal links. It may be that the more severely affected are unable to access services, or that those who have accessed services feel more satisfied with their QoL. Whatever the case, the fact that one-third of disabled people report that they need rehabilitation but have not received it is a cause for concern.

The limitations of the study include the need to rely on self-report which may have over- or under-estimated the need and/or access. In addition, those interviewed might represent the most severe end of the disability spectrum. A further limitation is that facilitors were not analysed or presented in conjunction with the barriers, so that service providers would know what is currently working.

The results of this study indicate an urgent need to improve access to rehabilitation services, including the provision of assistive devices to people with disability living in this impoverished area. Home-based care and vocational training in particular were identified as being required. A programme is currently underway to train home-based carers to meet the needs of the community. However, it would be important that the training incorporates all aspects of community-based rehabilitation to ensure that both environmental issues and the need for rehabilitation and vocational training are addressed. It may be important that the rehabilitation care worker be supported by a network of therapists who are able to guide, train and supervise them in the management of patients who require specialist support.

The local authorities seem to have made reasonable headway with the provision of health care services, however the provision of rehabilitation services that impact positively on the QoL of

people with disabilities appears to be lagging behind. Where services are minimal, basic rehabilitation services should be developed within the existing health infra-structure [1]. In the light of the relative accessibility of health care services, this might be a very useful strategy. The training of home-based carers as community-based rehabilitation workers is another strategy that could be employed, as discussed above. However it should be remembered that South Africa is categorised as a middle and not a low income country, with the expectation that the sophisticated service coverage available to those with higher incomes can ultimately be expanded and the service quality improved.

10 Validation of the WHODAS-2 and the WHOQOL-BREF

10.1 Translation process

The forward and back translation process prescribed by the WHO aims to achieve cross-cultural and conceptual equivalence rather than linguistic equivalence [95] (Figure 36). The process appears to incorporate the Universalist approach, which allows for the exploration of constructs within cultures and context. The Universalist approach assumes that constructs within instruments might have different meanings across cultures and therefore might change during translation [318]. In contrast, the Absolutists disregard the cultural influence, and assume that constructs will remain constant [318]. The cognitive exploration of constructs in the WHO process posed some difficulties during the translation and testing of the instruments in the current study. The WHO outlines 4 phases [95]:

- Forward translation
- Expert panel back-translation
- Pre-testing and cognitive interviewing
- Final version

An occupational therapist and physiotherapist, with research expertise in disability, were employed to conduct the forward translation process of the isiXhosa versions of the instruments. Two Afrikaans language experts, teaching in the Department of Health and Rehabilitation Sciences, translated the Afrikaans versions. There were no discrepancies identified with the translation process during the expert-panel committee meetings that included the translators, the researcher and the language experts from the University of Stellenbosch. he main role of the expert group was to check for semantic, idiomatic, experiential and conceptual equivalence between the back translated version and original version of the instrument [319]. Language experts did the back- translation process from the University of Stellenbosch. Even though no language issues were identified during the translation process, the appropriateness of some of the questions in the respective instruments was queried during the cognitive debriefing and testing of the instruments.

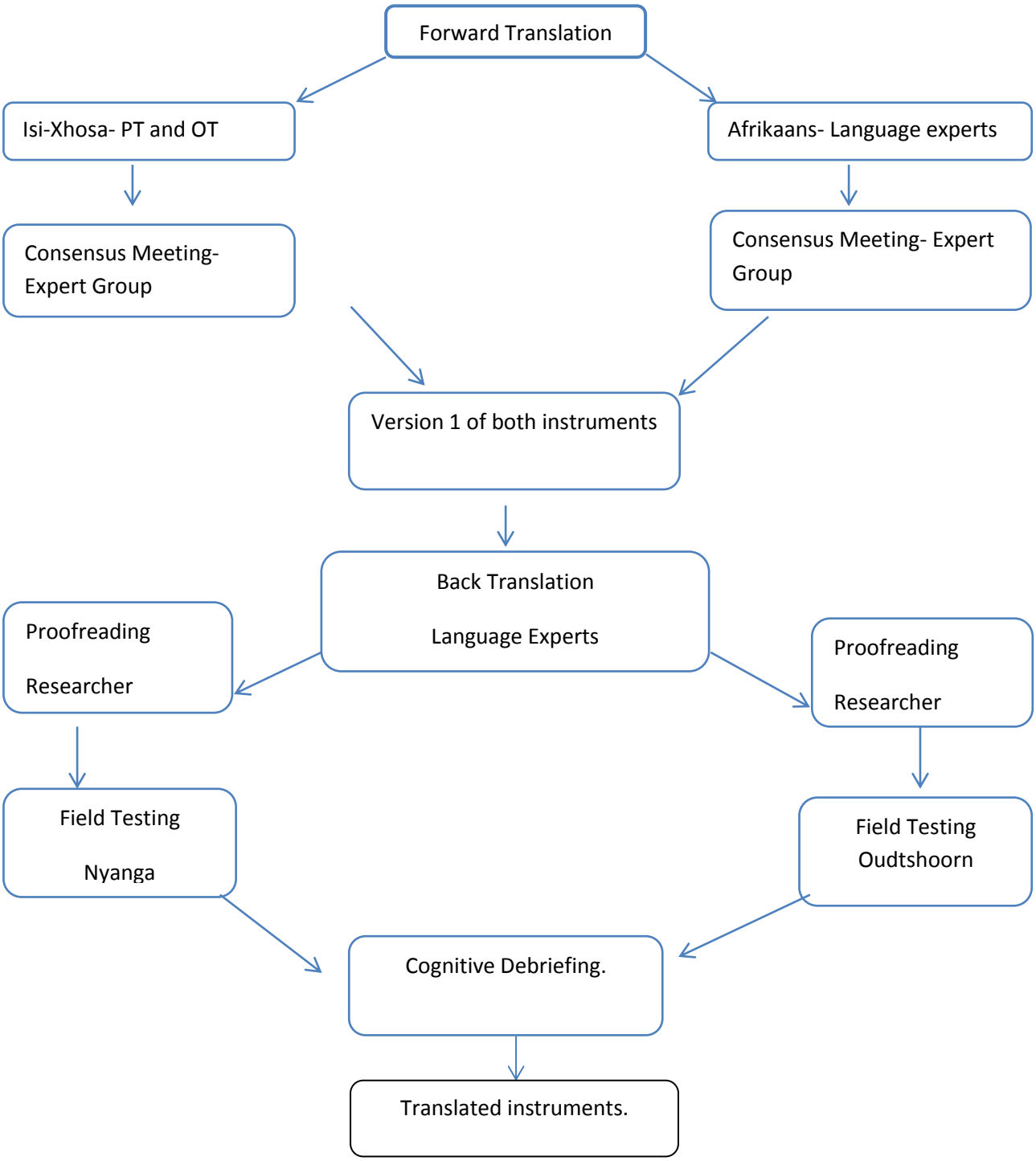


Figure 36: Diagrammatic representation of the translation process

Questions related to sexual activity were difficult for both the enumerators and the respondents. It was considered impolite to ask those older than yourself about their sex life. The enumerators were duly trained on the administration of the instruments, with clear guidance on how to pose questions about sex life without being offensive, and to allow those who felt uncomfortable not to respond. The researchers did not consider changing the question, as sexual activity forms an integral part of functioning and could be affected by disability. It was anticipated that even those who had trouble with the questions would respond to them.

10.2 Validation of the WHODAS-2 and the WHOQOL-BREF

Post hoc analysis was done to examine the internal consistency and reliability, construct validity and concurrent validity of the Afrikaans version, which was answered by the Oudtshoorn respondents, and the isiXhosa version, which was answered by the Nyanga respondents.

10.2.1 Reliability of the WHODAS-2

In all, 288 adults answered the WHODAS-2. The survey methodology is described in Chapter 4 and only the results as they pertain to the WHODAS-2 are included in this section.

Analysis was performed for the entire group and then separately for the Afrikaans and isiXhosa versions. As so few respondents were employed, the questions relating to employment under life activities were excluded. The internal consistency for the scale as a whole was high (Cronbach's alpha =0.950; N=267) (Table 40). The internal consistency of all domains ranged between 0.81 and 0.95 and almost all items correlated well with the domain scores. All items correlated well within their own domain except for Eating and Staying alone in the Self-care domain, and Sexual activity in the Getting along domain. The item on sexual activity correlated less well with the other items in the domains. The results for the two language versions are presented below. Cronbach`s alpha was lower in Oudtshoorn (0.78) in the Getting Along domain, compared to that in Nyanga (0.82).

The Internal consistency of the WHODAS-2 was above 0.75 in all domains in the two sites, which demonstrates acceptable consistency [320].

Table 40: Internal consistency of the WHODAS-2 (N=288, missing = 93)

Domain and items	Cronbach's alpha Oudtshoorn	Cronbach's alpha if item deleted	Cronbach's alpha Nyanga	Domain mean if item deleted
Total Scale	**0.95**		**0.95**	
Understanding and Communicating	**0.93**		**0.91**	
N	169		166	
Concentrate		0.91		0.90
Remember		0.92		0.89
Analyse		0.91		0.88
Learn		0.92		0.89
Understand spoken words		0.92		0.89
Maintain conversation		0.92		0.88
Getting around	**0.92**		**0.94**	
N	171		160	
Standing for long periods		0.90		0.92
Sit to stand		0.90		0.93
Moving around in home		0.90		0.93
Getting out of the home		0.90		0.93
Walking long distances		0.91		0.93
Self-care	**0.88**		**0.83**	
N	174		157	
Washing		0.80		0.80
Dressing		0.79		0.79
Eating		0.91		0.91
Staying alone		0.85		**0.85**
Getting along	**0.78**		**0.82**	
N	158		144	
Unknown people		0.69		0.80
Maintaining friendships		0.67		0.74
Close people		0.74		0.79
Making new friends		0.68		0.74
Sexual Activity		0.91		0.86
Life activities	**0.95**		**0.94**	
N	171		157	
Household responsibilities		0.95		0.92
Household tasks		0.92		0.91
Household work		0.92		0.90
Household work quickly		0.94		0.93
Participation	**0.83**		**0.83**	

N	166		154	
Community activities		0.80		0.82
Barriers in the world		0.79		0.80
Dignity		0.81		0.83
Health condition		0.81		0.80
Financial resource		0.81		0.80
Family Problem		0.82		0.80
Relaxation/Pleasure		0.81		0.80

10.2.2 Construct validity of the WHODAS-2 Domains

Construct validity was examined through the use of confirmatory factor analysis with Varimax rotation on the Afrikaans (Oudtshoorn) and isiXhosa (Nyanga) responses. Varimax rotation identifies factors that are not correlated with each other. The number of factors was constrained to six to represent the different domains of the WHODAS-2. The domains identified by the WHODAS-2 developers emerged during factor analysis with Varimax Normalised Rotation. In confirmatory factor analysis, "loadings should be 0.7 or higher to confirm that independent variables identified a priori are represented by a particular factor, on the rationale that the 0.7 level corresponds to about half of the variance in the indicator being explained by the factor" [295]. Items that loaded as 0.6 or more are marked in the following tables.

For the Afrikaans version, there were 173 complete responses and the item loadings, which indicate the correlation of each item with that factor, are given in

Table 41. Of the 32 items, four did not load more than .6 on any of the six factors: Eating, Community Activities, Barriers in the World and Family problems. Only two items loaded on more than one factor, Understanding spoken words and Maintaining a conversation (Understanding and Getting Along). Factors were identified that clearly supported the Domains of Getting Around, Getting Along, Participation and Understanding. However the items in the domains of Self-care and Life Activities domains loaded on a single factor and Sexual Activity was the only item which loaded on Factor 5, indicating that it did not correlate well with any other items.

As can be seen in Table 40, the Getting Around domain accounted for 56% of the total variance in the WHODAS-2 scores.

Table 41: Loading of each item on the 6 factors of the WHODAS-2 Afrikaans version (N=173)

Afrikaans	Factor1	Factor 2	Factor 3	Factor 5	Factor 4	Factor 6
	Getting around	**Getting along**	**Self care/ Life activities**	**Sexual activities**	**Participation**	**Understanding**
Concentrate	0.1	0.4	0.1	0	0.2	***0.8***
Remember	0	0.3	0.1	0	0.2	***0.8***
Analyse	0.1	0.3	0.2	0.1	0.2	***0.8***
Learn	0.2	0.3	0.3	0.2	0.1	***0.7***
Understand spoken words	0	***0.6***	0.2	0	0.2	***0.6***
Maintain conversation	0	***0.6***	0.1	0.1	0.1	***0.6***
Standing for long periods	***0.9***	0	0.2	-0.1	0.1	0.1
Sit to stand	***0.8***	0	0.2	0	0.2	0
Moving around in home	***0.8***	0.1	0.3	0	0.2	0.2
Getting out of the home	***0.8***	0.1	0.2	0.1	0.2	0.2
Walking long distances	***0.8***	0	0.1	0.1	0.2	-0.1
Washing	0.2	0.2	***0.9***	-0.1	0.1	0.2
Dressing	0.2	0.2	***0.8***	-0.1	0.1	0.2
Eating	*0.2*	*0.4*	*0.5*	*0*	*0.3*	*0.1*
Staying alone	0.3	0.3	***0.7***	0.1	0.1	0.2
Unknown people	0	***0.8***	0.2	0	0.1	0.3
Maintaining friendships	0.1	***0.9***	0.1	0.1	0.1	0.3
Close people	0	***0.7***	0.3	-0.1	0.3	0.3
Making new friends	0.1	***0.8***	0	0.1	0.1	0.2
Sexual activity	0.1	0.2	0.1	***0.8***	0.1	0.2
Household responsibilities	0.3	0.1	***0.6***	0.3	0.4	0.2
Household tasks	0.4	0	***0.7***	0.3	0.3	0.2
Household work	0.5	0	***0.6***	0.3	0.3	0.2
Household work quickly	0.5	-0.1	***0.6***	0.4	0.3	0.2
Community activities	*0.3*	*0.4*	*0.2*	*0.4*	*0.5*	*0*
Barriers in the world	*0.4*	*0.3*	*0.2*	*0.4*	*0.5*	*0.1*
Dignity	0	0.3	0.3	0	***0.6***	0.2
Health condition	0.4	0.1	0.2	-0.1	***0.6***	0.2
Financial resource	0.3	0.1	-0.1	-0.1	***0.7***	0.2
Family problem	*0.3*	*0.2*	*0.3*	*-0.4*	*0.4*	*0.3*
Relaxation/pleasure	0.1	0.1	0.4	0.2	***0.6***	0.1
Explained variance	**5.2**	**4.7**	**4.9**	**3.0**	**1.7**	**3.8**
Proportion of variance	**0.2**	**0.2**	**0.2**	**0.1**	**0.1**	**0.1**

Table 42: Loadings of each item on the six factors of the WHODAS-2 isiXhosa version (N=120)

isiXhosa	Factor1	Factor 2	Factor 3	Factor 5	Factor 4	Factor 6
	Understanding	**Getting around/ Self-care**	**Participation**	**Life activities/ Getting along**	**Getting along**	**Sexual activity**
Concentrate	***0.6***	0.1	0.3	0.2	0.2	0.2
Remember	***0.7***	-0.1	0.3	0.2	0.1	0.3
Analyse	***0.7***	0.2	0.1	0.3	0.0	0.3
Learn	***0.6***	0.0	0.1	0.4	0.2	0.0
Understand spoken words	***0.7***	-0.1	0.0	0.3	0.3	-0.2
Maintain conversation	***0.8***	0.0	0.1	0.1	0.3	0.0
Standing for long periods	0.0	***0.9***	0.0	0.1	0.0	0.2
Sit to stand	-0.1	***0.9***	0.1	0.1	0.0	0.0
Moving around in home	0.1	***0.9***	0.2	0.2	0.1	0.1
Getting out of the home	0.2	***0.8***	0.2	0.3	0.0	0.0
Walking long distances	-0.1	***0.8***	0.0	0.1	0.0	0.0
Washing	0.2	***0.6***	0.2	0.3	0.4	0.2
Dressing	0.2	***0.6***	0.2	0.2	0.4	0.1
Eating	*0.2*	*0.4*	*0.3*	*0.1*	*0.5*	*0.1*
Staying alone	*0.1*	*0.4*	*0.2*	*0.5*	*0.0*	*0.4*
Unknown people	0.3	0.0	0.2	***0.7***	0.3	-0.1
Maintaining friendships	0.2	0.0	0.1	***0.6***	***0.6***	0.1
Close people	0.3	0.1	0.0	0.1	***0.8***	0.1
Making new friends	0.2	0.0	0.0	0.4	***0.6***	0.3
Sexual activity	0.2	0.1	0.0	0.2	0.2	***0.8***
Household responsibilities	0.4	0.3	0.1	***0.7***	0.1	0.2
Household tasks	0.4	0.4	0.1	***0.7***	0.1	0.1
Household work	0.3	0.4	0.1	***0.8***	0.1	0.1
Household work quickly	0.2	0.4	0.0	***0.7***	0.2	0.2
Community activities	*0.3*	*0.4*	*0.2*	*0.4*	*0.3*	*-0.1*
Barriers in the world	*0.5*	*0.3*	*0.2*	*0.4*	*0.1*	*-0.2*
Dignity	*0.1*	*0.0*	*0.2*	*0.5*	*0.1*	*0.2*
Health condition	0.4	0.2	***0.7***	0.1	0.0	0.0
Financial resource	0.2	0.0	***0.9***	0.1	0.0	0.0
Family problem	0.0	0.1	***0.8***	0.2	0.1	-0.1
Relaxation/pleasure	-0.1	0.2	***0.6***	0.4	0.2	0.3
Explained variance	**4.4**	**5.6**	**3.1**	**5.0**	**2.6**	**1.6**
Proportion of variance	**0.1**	**0.2**	**0.1**	**0.2**	**0.1**	**0.1**

There were 120 completed responses to the isiXhosa version and the item loadings are given in

Table 42. Of the 32 items, five did not load more than 0.6 on any of the six factors: Eating, Staying Alone, Community Activities, Barriers in the World, Living with dignity and Family problems. Maintaining friendship loaded on more than one factor. Factors were identified that clearly supported the domains of Understanding, Getting Around and Life Activities. Several of the Getting Along items loaded on a factor which included Life activities, while and Self-care Items loaded on the same factor as Getting around. As with the Afrikaans version, Sexual activity was the only item which loaded on its own factor, indicating that it did not correlate well with any of the other items.

10.2.3 Reliability of the WHOQOL-BREF

The Cronbach's alpha for the WHOQOL-BREF as a whole was 0.889 (see Table 43). All items were completed by 301 participants.

Table 43: Internal consistency of the Afrikaans and isiXhosa versions of the WHOQOL-BREF

Domain	Cronbach's alpha Oudtshoorn	Cronbach's alpha if item deleted	Cronbach's alpha Nyanga	Cronbach's alpha if item deleted
Total scale	**0.83**		**0.90**	
N	123		115	
Physical	**0.43**		0.87	
Pain		0.27		0.86
Medical treatment		***0.68***		0.87
Energy		0.34		0.85
Get Around		0.40		0.85
Sleep satisfaction		0.29		0.86
Performing ADL		0.34		0.84
Work Capacity		0.23		0.84
Psychological	**0.61**		0.77	
N	166		135	
Enjoy Life		***0.76***		0.69
Meaningful Life		0.50		0.72
Concentration		0.48		0.72
Bodily Appearance		0.52		0.78
Abilities		0.49		0.71
Depression		0.52		0.77
Social	**0.64**		0.69	
N	132		95	
Personal Relationships		0.61		0.35
Sex Life		0.39		0.44
Friends		0.64		0.82
Environment	**0.63**		0.73	
N	168		135	
Safe		0.63		0.68
Healthy Environment		0.59		0.66
Money		0.58		0.68
Information availability		0.64		0.69
Leisure Activities		0.61		0.71
Living Space		0.57		0.69
Access to Health Care		0.59		0.72
Transport		0.55		0.74

10.2.4 Construct validity of the WHOQOL-BREF

The Item related to Sexual activity was removed, as 74 respondents did not answer this question. In the Afrikaans version, items from each domain did not load onto corresponding factors (Table 44). Factors 1 and 2 included items from all four domains. Factor 3 included three of the Environmental items but the other five items either did not load on any factor or were spread across the other three factors.

Similarly during factor analysis of the isiXhosa version, items in each domain loaded under different factors (Table 45). However, the isiXhosa version performed better in that some clearly identifiable factors did emerge. Six of the seven physical domain items loaded on Factor 1, but Psychological and Environmental items were also included here.

Table 44: Factor loading of the Afrikaans version of the WHOQOL-BREF items (N=123)

Afrikaans	Domain	Factor 1	Factor 2	Factor 3	Factor 4
Pain	Physical	0.5	0.2	0.0	0.2
Medical treatment	Physical	***-0.6***	0.4	0.0	-0.1
Energy	Physical	0.2	***0.7***	0.2	-0.2
Get Around	Physical	0.1	0.1	0.1	***0.7***
Sleep	Physical	***0.6***	0.1	0.0	0.4
Performing ADL	Physical	0.5	0.3	0.0	-0.2
Work Capacity	Physical	***0.8***	0.2	0.1	0.2
Enjoy Life	Psychological	***-0.6***	0.3	0.2	0.2
Meaningful Life	Psychological	0.5	0.2	0.3	0.1
Concentration	Psychological	0.3	***0.6***	0.3	0.2
Bodily Appearance	Psychological	***0.6***	0.4	0.1	0.2
Self-satisfaction	Psychological	***0.7***	0.2	0.2	0.3
Depression	Psychological	0.3	0.0	0.4	0.5
Personal Relationships	Social	***0.6***	0.1	0.3	0.3
Friends	Social	0.1	***0.6***	-0.1	0.3
Healthy Environment	Environmental	0.1	***0.7***	0.1	-0.1
Money	Environmental	***0.6***	0.2	0.2	0.0
Information availability	Environmental	0.2	0.1	0.3	0.4
Leisure Activities	Environmental	0.1	-0.1	0.0	***0.7***
Living Space	Environmental	0.0	0.2	***0.7***	0.1
Access to Health Care	Environmental	0.1	0.0	***0.8***	-0.1
Transport	Environmental	0.0	0.0	***0.7***	0.3
Safe	Environmental	0.1	0.5	-0.3	0.4
Explained variance		4.5	2.6	2.5	2.4
Proportion of variance		0.2	0.1	0.1	0.1

Table 45: Factor loading of the isiXhosa version of the WHOQOL-BREF items

Nyanga		Factor 1	Factor 2	Factor 3	Factor 4
		Physical		Psychological	Environmental
Pain	Physical	***0.7***	0.0	-0.1	0.2
Medical treatment	Physical	***0.6***	-0.1	0.3	0.0
Energy	Physical	***0.6***	0.3	0.4	0.1
Get Around	Physical	***0.8***	0.2	0.1	0.0
Sleep	*Physical*	*0.4*	*0.4*	*0.5*	*0.2*
Performing ADL	Physical	***0.8***	0.3	0.1	0.2
Work Capacity	Physical	***0.8***	0.3	0.2	0.1
Enjoy Life	Psychological	0.4	0.1	***0.6***	0.1
Meaningful Life	Psychological	0.3	-0.1	***0.7***	-0.1
Concentration	Psychological	***0.6***	-0.2	0.5	0.3
Bodily Appearance	Psychological	0.3	***0.6***	0.2	0.1
Self-satisfaction	Psychological	***0.7***	0.2	0.3	0.4
Negative feelings	Psychological	0.1	0.1	***0.7***	0.1
Personal Relationships	Social	0.0	0.2	***0.6***	0.1
Friends	*Social*	*0.1*	*0.4*	*0.4*	*0.2*
Safe	Environmental	0.1	-0.1	0.5	***0.6***
Healthy Environment	Environmental	0.3	0.0	0.1	***0.8***
Money	Environmental	0.2	0.1	0.2	***0.6***
Information availability	*Environmental*	*0.3*	*0.0*	*0.3*	*0.4*
Leisure Activities	Environmental	***0.7***	-0.1	0.3	0.1
Living Space	Environmental	0.0	0.2	-0.1	***0.8***
Access to Health Care	Environmental	-0.1	***0.8***	0.2	0.2
Transport	Environmental	0.1	***0.7***	-0.1	-0.1
Explained variance		**4.99**	**2.14**	**3.30**	**2.64**
Proportion of variance		**0.22**	**0.09**	**0.14**	**0.11**

10.2.5 Concurrent validity: comparison between WHODAS-2 and WHOQOL-BREF using the EQ-5D as dependent variable

The total scores of the WHODAS-2 and the WHOQOL-BREF correlated with both the EQ-5D index score (derived from self-report responses to the domain items) and the EQ-5D VAS (a measure of perceived global health status). This was the case for the whole sample (Figure 37), for the Afrikaans version (Table 46 and Figure 38) and for the isiXhosa version (Table 47 and Figure 39).

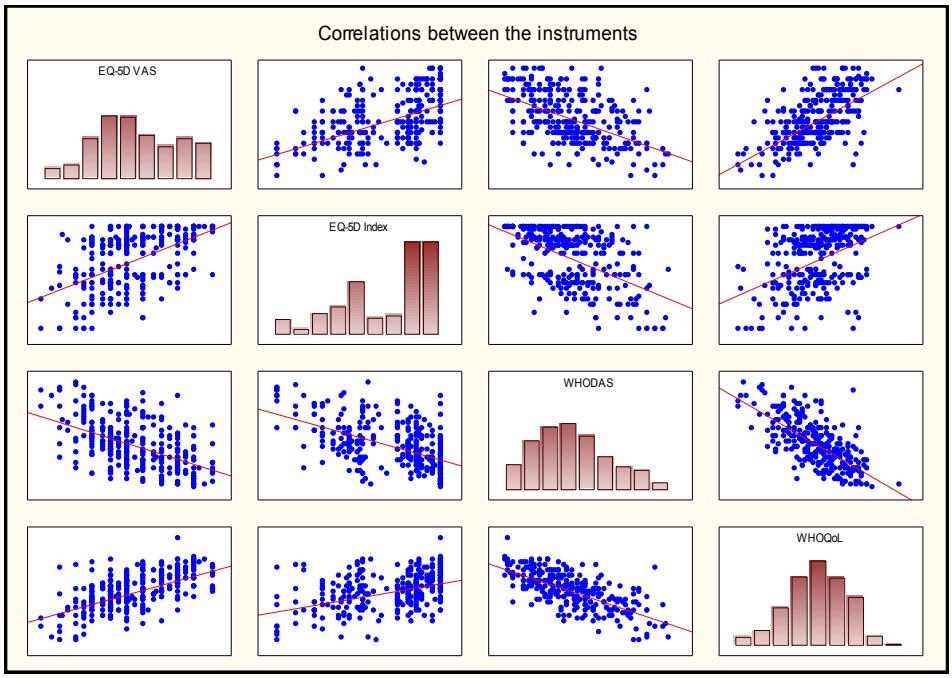


Figure 37: Scatterplots of the scores from WHODAS-2, WHOQOL-BREF, EQ-5D VAS and index score

Table 46: Correlations (Pearson's r) between WHODAS-2, WHOQOL-BREF, EQ-5D VAS and Index scores-Afrikaans version (153)

	EQ-5D VAS	EQ-5D Index	WHODAS-2	WHOQOL-BREF
EQ-5D VAS		0.462	-0.420	0.464
EQ-5D Index	0.462		-0.356	0.253
WHODAS-2	-0.420	-0.356		-0.712
WHOQOL-BREF	0.464	0.253* (p=0.002)	-0.712	

Note: the higher the WHODAS-2 score, the worse the QoL
* P<.001 in every case apart from this.

Figure 38: Scatterplots of the scores from WHODAS-2, WHOQOL-BREF and EQ-5D VAS and index score - Afrikaans version (N=153)

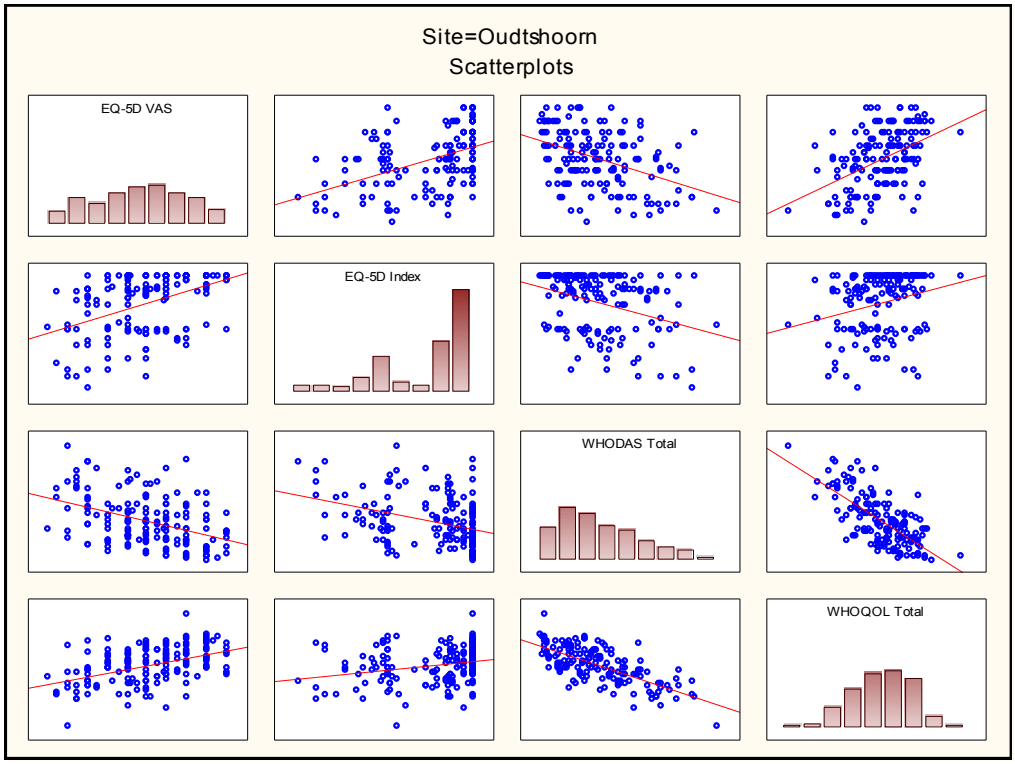
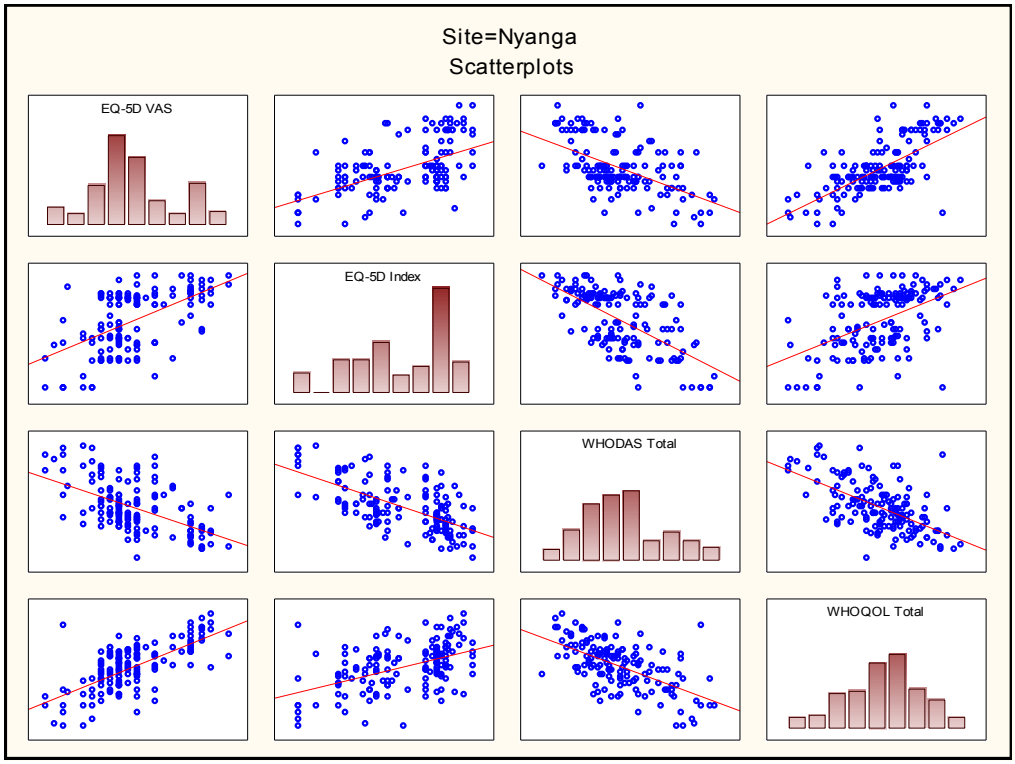


Table 47: Correlations (Pearson`s r) between WHODAS-2, WHOQOL-BREF, EQ-5D VAS and Index score- isiXhosa version (N=144)

	EQ-5D VAS	EQ-5D Index	WHODAS-2	WHOQOL-BREF
EQ-5D VAS		0.550	-0.548	0.691
EQ-5D Index	0.550		-0.643	0.486
WHODAS-2	-0.548	-0.643		-0.602
WHOQOL-BREF	0.691	0.486	-0.602	

Note: the higher the WHODAS-2 score, the worse the QoL
p>0.001 in every case.

Figure 39: Scatterplots of the scores from WHODAS-2, WHOQOL-BREF, EQ-5D VAS and index score - isiXhosa version (N=144)



To determine whether the instruments give redundant information, forward stepwise multiple regression was used to compare the predictive value of each instrument against the EQ-5D scores. The WHODAS-2 was the best predictor of the EQ-5D index score and accounted for 26% (Multiple r^2=0.26) of the variance, compared to only 1% (0.014) by the WHOQOL-BREF (Table 48). However, the WHOQOL-BREF was the best predictor of the EQ-5D VAS scores and accounted for 38% (0.377) of the variance, compared to only 2% (0.018) by the WHODAS-2.

Table 48: Regression analysis with EQ-5D scores as dependent variables

Dependent variable		Multiple (R-square)	R-square (change)	F - to (entr/rem)	p-value
Index score	WHODAS-2	0.264	0.26	112.0	0.000
	WHOQOL-BREF	0.277	0.01	5.9	0.016
VAS	WHOQOL-BREF	0.377	0.377	178.7	0.000
	WHODAS-2	0.395	0.018	8.5	0.004

10.3 Discussion: psychometric properties of WHODAS-2 and WHOQOL-BREF

The WHOQOL-BREF and the WHODAS-2 have been extensively used in various health conditions and settings [169, 208, 321-327]. According to its developers, the WHODAS-2 addresses the need for a cross-cultural standardised instrument to measure health and disability across six domains namely cognition, mobility, self-care, getting along, life activities and participation [197]. Its psychometric properties were tested during its development across 19 countries and it was found to be a reliable and valid instrument [197]. The WHOQOL-BREF has the primary aim of assessing QoL across the domains of physical health, psychological health, social relationships and environment. It has also been tested across various countries and cultures during its development [328]. The items of the two instruments tend to overlap in some domains, which is to be anticipated, as the constructs of functioning and well-being are compatible. In resource-constrained areas, it might be advisable to have only one instrument to measure disability-specific aspects rather than two. Both instruments showed excellent internal consistency in the current context. The global score reached the standard of 0.95 for individual comparisons, suggesting that the items were reliable for the context [329].

As found in other studies, the WHODAS-2 items correlated well within each domain, achieving an intra-class correlation coefficient of 0.8-0.95 at domain level and a corrected item correlation coefficient of 0.6-0.91 [297, 330]. The items with the lowest item-total correlation that did not fit the model were Eating and Staying alone in the Self-Care domain, and Sexual activity in the Getting Along domain. Some of these items reflected similar characteristics in other studies [209]. The WHODAS-2 domains were supported by factor analysis, suggesting that the domains identified by the developers are valid within this context. The item of Sexual activity had to be removed from factor analysis as many (more than 70 respondents) did not answer this question. The non-response to this question raises concerns about its appropriateness, and whether a different question should be considered to explore sexual activity in this context. The topic is a sensitive one in areas with strong cultural norms, and has been problematic in countries such as Japan and Uganda [331, 332].

The Taiwanese short version of the WHOQOL-BREF also showed poor factor structure, suggesting that the domain structure is not valid across all cultures and health conditions [333]. As in other studies, we found that the domains were not supported by a 4-factor analysis, and would possibly better fit a 6-factor structure. Items such as “How much do you

need medical treatment to function in your daily life?" are scored in the Physical domain but did not load into the same factor as other physical items. Sleep (Physical domain) loaded higher with the factor that mostly included Psychological items, while four of the Environmental items loaded onto a factor that included most of the Physical domain items [328]. Although three of the factors could be identified as representing the latent constructs of Physical and Psychological functioning and Environmental, no Social factor emerged – possibly because only two items represent the Social domain. Sexual activity was excluded from analysis as very few respondents answered the question. Construct and divergent validity was not proven for the WHOQOL-BREF, however all factors obtained an Eigen value of >1. Factor 1, which represented most of the items associated with the psychological domain, obtained an Eigen value of 7. This domain also accounted for 30.5% of the variance of the entire scale.

The concurrent validity was good in that the correlations between the WHODAS-2, WHOQOL-BREF, EQ-5D VAS and EQ-5D index score were all highly significant, indicating that functioning and QoL are highly correlated. The WHODAS-2 was the best predictor of the EQ-5D index score and the WHOQOL-BREF was the best predictor of the EQ-5D VAS score. The WHOQOL-BREF has performed equally well with other QoL instruments such as the SF-36, indicating that it is a valid instrument for assessing overall well-being [297]. The high internal consistency of WHODAS-2 and WHOQOL-BREF indicate that the instruments are reliable and that the items included for the constructs of functioning (WHODAS-2) and QoL (WHOQOL-BREF) are appropriate. The WHODAS-2 appears to be more appropriate for future exploration of disability, however, as its domains are firmly based within the conceptual framework of the ICF and are valid in this context.

The high internal consistency of the WHODAS-2 and WHOQOL-BREF total scores, and the scoring algorithms based on item response theory, mean that the total scores can be used as interval data and hence parametric statistics (that assume normal data distribution) can be applied. The WHOQOL-BREF domains were not supported by factor analysis, however, and these scores should not be regarded as interval data. The WHOQOL-BREF does appear to measure the latent construct of HRQoL, but the scoring algorithm is open to questioning.

10.3.1 Conclusions

The translation process resulted in the development of two instruments that appear to be reliable and valid measures of the constructs they purport to measure. The use of the English, Afrikaans and isiXhosa versions in similar research settings to that of the current study is recommended. The total scores of WHODAS-2 and WHOQOL-BREF can be used as interval data

in parametric analysis, as can the domain scores of the WHODAS-2. The domain scores of the WHOQOL-BREF should be used with caution, however, particularly if parametric analysis is desired.

11 Discussion and Conclusion

This concluding chapter will not repeat the discussions from earlier chapters, but will instead summarise the main findings of the study and their implications. The research questions set out in Chapter 1 will be revisited and conclusions drawn from the study findings. The limitations of the current study in terms of methodology and generalisability will also be discussed. Finally, recommendations for practice and for future research are made, using the ICF framework to address each component of the disability experience.

The aim of this research was to explore the prevalence, nature and impact of disability in two under-resourced towns in the Western Cape, one urban and the other semi-rural. The two areas differed significantly in both prevalence and nature of disability, suggesting that context matters in the quantification of disability.

11.1 Major findings: Screening sample

11.1.1 Prevalence of disability

In all, 645 individuals screened positive for having difficulty in any one of the domains of seeing, hearing, walking, self-care, remembering and concentrating, and communication. This represented a prevalence rate of 9.7% (CI 9.0-10.4%). A significantly smaller proportion of respondents were identified as having disability in Oudtshoorn (244, 6.8%; CI 5.9-7.6%) compared to Nyanga (401, 13.1%; CI 12.0-14.3%; Chi-sq=77.8, $p<0.001$).

These prevalence rates can be accepted as a true reflection of the actual rates, as the precision of the disability estimates was 99%. The sampling strategy resulted in respondents with disability who were representative of their respective districts and the Western Cape, i.e. the majority were female and in the age group 55-85 years as in the 2011 Census [334] [62]. However, the results can only be extrapolated to the lower income strata in both areas. As the screening instrument is not applicable to children under the age of five years, a major limitation of the study is that the prevalence rate does not include a very vulnerable group, young children.

The results show that small-scale surveys can provide more nuanced data on disability prevalence than the national census. Contrary to the literature, the urban area was found to have higher prevalence rates of disability than the rural area [8, 195]. In addition, the disability prevalence in both survey areas was higher than the 5.7% estimate for the Western Cape province [62]. The pattern of disability was different between the two survey areas, with the Oudtshoorn respondents reporting more severe functional limitation. Nyanga had more middle-aged people with disability (81%) and Oudtshoorn had relatively more elderly and youth with disability (31%). This could be anticipated, as Oudtshoorn had many more elderly in their sample compared to Nyanga and had a higher care dependency ratio. This is consistent with the 2011 Census, which found Oudtshoorn to have many more people over the age of 65 years compared to other districts in the province [69] [69]The higher percentage of middle-aged adults in Nyanga is consistent with the migration to urban areas of younger people seeking employment [70].

These varying patterns of disability have different implications in the two areas. In Nyanga where the household size is relatively small, there are more adults with disability who should be wage earners and fewer people living in the same home to provide care. In Oudtshoorn, there is a high care dependency ratio and the adults are already supporting more youth and elderly with disability than in Nyanga. This, coupled with the severe degree of disability, means that there is a heavy burden of care on these adults, with consequences for their own capacity for full-time employment and for the household income.

11.2 Nature of Disability

The convenience sample of people with disability who were interviewed did not differ significantly from the initial sample with regard to severity of disability, gender, employment and receiving a grant. However the group that was interviewed was slightly older (but not significantly so), which could bias the experience of disability to reflect a view more related to the elderly. The mean age of those interviewed was 49 years, compared to 36 years for the initial sample of people identified with disability.

11.2.1 Types of disability

Difficulties with walking were the most prevalent functional limitation in both areas (60-80%). In contrast, the 2011 National Census using a similar methodology found visual difficulties to be the most prevalent functional disability [62]. Disability in the form of walking difficulties is

more common in areas with a high percentage of elderly people [263, 335-337], which is not the case in Nyanga. However, previous studies conducted in Cape Town that included Nyanga in the sampling have also noted a high prevalence of mobility problems [121]. More than 80% of the current sample answered that they had adequate access to health care, which could reduce the prevalence of preventable and corrective visual impairments. The prevalence of walking difficulties could also be explained by intentional and unintentional trauma as major causes of disability. Head injuries can be associated with difficulties in walking and concentration, which seems to reflect the experiences in Nyanga.

11.2.2 Causes and burden of disability

Non-communicable diseases contributed to the greatest burden of disability, followed by communicable disease and unintentional trauma. These findings are similar to those of the Global Burden of Disease report [112]. The burden of disability was much greater in Nyanga than in Oudtshoorn, primarily due to the Nyanga respondents reporting a higher decrement in HRQoL for each health condition.

The two sites differed significantly in the cause of disability and the burden associated with disability. People with disability in Oudtshoorn were most likely to attribute their disability to non-communicable diseases, while in Nyanga it was more often attributed to intentional trauma. The national prevalence of non-communicable diseases is high in urban and rural areas, but disproportionately among the urban poor [338]. The increased likelihood of non-communicable disease as a cause of disability in both areas may be related to complications of diabetes and hypertension due to poor management of these conditions [282] and the higher prevalence in Oudtshoorn may be due to the older population [339]. Economic stressors seemed more evident in the urban group (Nyanga), which reported a far higher burden of disease due to disability (1632 healthy years of life lost compared with 930 in Oudtshoorn).

Mental health problems are a large contributor to the burden of disease in the Western Cape [16, 134], but contributed surprisingly little to the burden in this study. This was possibly due to a lack of sensitivity of the instrument (Washington Group Set Short questions) to cognitive impairment or a poor understanding of mental health among the respondents as a possible cause of impairment, which led to under-reporting of this condition.

Many of the factors mentioned as causes of disability in this study are mentioned in the literature as consequences of rapid urbanisation, globalisation and neo-liberal economic policies [123, 180, 340, 341], which are common in emerging economies such as South Africa [342]. A high prevalence of disability due to unintentional trauma, anxiety and mental health

has also been attributed to the process of urbanisation [346]. Alcohol and drug abuse appears to be common in these areas and also fuel the trauma burden [347]. Care services should therefore not be limited to physical rehabilitation but should also include prevention and health education, with a larger focus on the determinants of disability and disease.

11.2.3 Functional limitations

The greatest number of functional limitations, for the sample as a whole and for the individual sites, were in the WHODAS-2 domains of Getting Around and Life Activities, indicating that physical ability was the most affected. Demographic factors of age, gender and site were not good predictors of the overall WHODAS-2 score, although living in Oudtshoorn predicted a 10% decrease in score. Apart from Self-care, the domains predicted the Participation domain well, with Cognition emerging as the strongest predictor, possibly because those who had severe cognitive problems were likely to be the most impaired. The Oudtshoorn respondents reported better functioning, as evidenced by lower (better) scores on every domain, and their total mean score was more than 10% less than Nyanga. The rank order of domain scores was broadly similar in the two areas, with the greatest score differences being for Cognition, Getting Along and Participation, these are the domains in which interaction with others is most required.

11.2.4 Quality of life and Health-related quality of life

As with the WHODAS-2, Oudtshoorn respondents scored higher (better) in every domain in the WHOQOL-BREF. The impact of context was also evident in the finding that the largest difference in medians (3) was in the Environmental domain. On the EQ-5D, the Nyanga sample reported most problems in the domains of Pain/Discomfort (74%) and Anxiety/Depression (72%), while the Oudtshoorn sample reported most problems on Usual Activities (52%) and Pain/Discomfort (51%). Once again the Oudtshoorn sample reported fewer problems in every domain and this was reflected in a significantly higher EQ-5D index score. The mean EQ-5D VAS score was 54.6 and as more than half of the Nyanga respondents scored between 20 and 50, their mean VAS score was 10% less than that of the Oudtshoorn residents. However, regression analysis revealed that if the domain scores were equivalent, there was no difference in VAS between the two sites. In other words, function rather than site was the greatest determinant of HRQoL. Being employed raised the VAS score by ten points, whereas having problems with Mobility, Pain/Discomfort or Anxiety/Depression lowered it significantly. The coefficient for Anxiety/Depression was -12 for each level; this implies that the score of someone who was extremely anxious or depressed would be 24% lower. This could account

for the non-significant impact of site, as Anxiety/Depression was reported more frequently in Nyanga.

The large number of respondents in Nyanga who reported problems with Anxiety/Depression on the EQ-5D and the WHOQOL-BREF again points to the strong possibility that mental health problems were under-reported, particularly in the urban context.

11.2.5 Environmental factors and Access to services

11.2.5.1 Employment and income

Even though many of those with disability who were interviewed were still in the economically active age group, less than half were employed. The reformist developmental welfare approach, used in South Africa to reduce poverty, seems to be effective in targeting those who need it, since most of those screened and interviewed were receiving a grant of some sort [156]. Although this approach ensures some income, it might not be sufficient to lift households out of poverty or to encourage economic independence, evident in the fact that Nyanga respondents in particular reported dissatisfaction with the money available to meet their needs. The majority of households reported an income considerably below the 2011 provincial average of R11,916, but consistent with the census data from Nyanga where approximately 75% of inhabitants reported a monthly income in the range of R1000-R3200 [343]. Despite attempts to improve the financial situation of people with disabilities through the disability grant, only minimal effort has been made to change the negative experience of disability, as many respondents reported barriers related to transport, the environment and discrimination and prejudice. The ideals expressed in the National Integrated Disability Strategy (1997) need to be revisited to ensure universal access and the equalisation of opportunities, especially with regard to employment for people with disabilities [344]. Employment does seem to be more available in Nyanga, as almost twice as many people were employed here compared to Oudtshoorn. However, improved employment opportunities do not seem to extend to people with disabilities, as only 20% of them were employed and the majority did not receive the vocational training that they needed to be employable.

Lack of employment for people with disabilities in an urban area adds to the cycle of poverty, as there is insufficient money for transport to access the services needed. The World Disability Report recognises that people with disability need to be able to access appropriate mainstream health care and rehabilitation to a greater extent than people without disability [1]. The lack of access to appropriate services, especially rehabilitation to address functional

limitations, has major implications on participation, especially for those living in under-resourced communities.

11.2.5.2 Access to services

Health and welfare services were received by most of them that needed it (99% and 80%, respectively). However, 53% of people with disabilities who needed medical rehabilitation had not received it, while home-based care services were not received by 67% of those needing them. A worrying finding was that the elderly were not accessing the services they needed. A major barrier identified by the Nyanga sample was the lack of "help in the home" and Prejudice and Discrimination. In addition, the demographic profile of Nyanga implies that there are fewer unemployed household members available to provide care to the elderly.

11.2.6 Validity and Reliability of the instruments

The instruments used in this survey were found to be valid for the context, however the WHODAS-2 showed better reliability and validity than the WHOQOL-BREF. The isiXhosa and Afrikaans-speaking communities had difficulty in responding to the WHOQOL-BREF questions about their sexuality, and similar results have been found in other African and Asian countries. It is therefore recommended that the WHODAS-2 be used in future research to explore functional status in South Africa.

11.3 Implications and recommendations

The study findings have implications at three major levels: policy-making, planning of local services and training of service providers.

11.3.1 Policy level

This study has demonstrated that small-scale surveys can provide more nuanced data on disability than national census data. The limitation of using census data in planning services for people with disabilities is that the prevalence in particular geographic areas could be underestimated and people with mild difficulties might be overlooked. Inaccurate estimates mean that those who are not counted will remain invisible and will not reach their full potential. It is acknowledged that the Western Cape Department of Health has been proactive in its community planning for people with disabilities, and have used the results of this survey to inform policy on intermediate and community-based care.

It is recommended that the national census be supplemented by smaller localised disability surveys for service planning. Appreciating the complications associated with screening children for disabilities, and the work already done by the Washington Group, it is recommended that the questions developed by the Washington Group be incorporated into surveys to establish

service needs among people with disabilities in specific communities. As mental health problems were not identified using our methodology, questions relating to mental health disturbances need to be included in the Census.

The results from the current study have further shown that the ideals and principles expressed in the National Integrated Disability Strategy (1997) have not been realised or appropriately implemented. People with disabilities are still marginalised with regard to universal access and adequate employment opportunities. As a signatory to the UN Convention on the Rights of Persons with Disabilities, South Africa has an obligation to ensure that people with disabilities are reasonably accommodated in the workplace and in society with the goal of achieving equal opportunities.

11.3.2 Service planners

A comprehensive approach should be adopted to address the needs of people with disabilities at community level, including curative, prevention, promotion and rehabilitative services. The impact of deprivation and previous disadvantage should be considered as health priorities, with special attention given to improving the environment of disadvantaged areas. Improvement of service delivery, particularly in the urban area, should be targeted. Attempts to reduce inequalities should have long term impact on the prejudice and discrimination experienced people and should become a government priority.

As most of the respondents related the cause of their disability to non-communicable diseases, attention should be paid to the prevention of further complications, as well as the promotion of healthy lifestyles among those residents not yet affected. Adequate rehabilitation should be in place to promote function, with assistive devices readily available especially to those with mobility difficulties. This will require services to be available at easily accessible community health centres, and a home-based service should be in place for those unable to access community services such as the elderly and severely disabled. Suitable posts will be needed for rehabilitation workers at varying levels and with a wide scope of practice, to improve accessibility and availability of specialised rehabilitation and home-based care.

The major causes of disability are related to rapid urbanisation, and services must do more than provide rehabilitation – they must also address determinants of disease in under-resourced areas. Collaboration between different sectors of government such as police, social development and health is needed to ensure a safe and supportive environment for people with disabilities.

11.3.3 Training of Service Providers

Those responsible for service provision need to be adequately trained to address the specific needs of people with disabilities. The Western Cape Department of Health identified the need for a rehabilitation cadre that could be trained in a relatively short period of time and could provide basic rehabilitation services under supervision of rehabilitation professionals [38]. This would provide the opportunity for home-based carers to be trained as community rehabilitation care workers (CRCW).

It is recommended that an approach similar to that of the University of Cape Town be adopted. The University was awarded the tender to pilot the training of 34 CRCWs in the Certificate in Disability Practice. The results of the current survey were used to develop a curriculum to enable home-based carers provide disabled people with basic services and intermediate care facilities. The curriculum targeted health promotion and prevention of chronic diseases of lifestyle; screening for impairments; rehabilitation management of functional limitations related specifically to mobility; advocacy and community empowerment to help participants be motivated for improved service delivery; and environmental changes. Two vital aspects of the programme are support for caregivers and improvement of the mental health of the recipients of services, particularly with regard to depression and anxiety.

The CRCW programme is currently only implemented in the Cape Town metropolitan area. It seems to be needed in other deprived areas as well, however, and should therefore be implemented nationally.

11.4 Limitations of the study

Despite all efforts to ensure a rigorous methodology, there were still limitations to the study.

The sampling method resulted in over-sampling of people living in informal dwellings in Nyanga. The number of people resident in informal dwellings decreased from 61% [9] in 2001 to 33 % in 2011 when the survey was undertaken [343]. Furthermore, the analysis could not take this factor into account, as the questionnaire did not allow the researcher to record the type of dwelling. The study results can therefore not be generalised to the entire population resident in Nyanga, but are more representative of the most disadvantaged in this area. Dwelling type was not used to stratify the sampling in Oudtshoorn so it is not certain whether residents of each dwelling type were proportionately represented. Therefore, although the two areas were selected based on deprivation, the fact that Oudtshoorn was not stratified in

terms of dwelling could have resulted in a less disadvantaged sample compared to that of Nyanga.

The Washington Group questions were framed differently in the two areas, and the degree of disability was only asked about in Oudtshoorn. Direct comparison of the degree of disability between the two sites was thus not possible.

As the instruments used to identify persons with disability were not appropriate for screening children, a major population group was excluded from the analysis. Similarly, the screening for mental health was inadequate and, in the light of the amount of depression reported, mental health problems are likely to be under-represented.

Not all the people identified with disability were followed up. Although no significant differences were found between the interviewed sample and the screened sample, the generalizability of the results to other people with disability living in the respective areas is thus questionable. The use of proxy respondents could have biased the reporting of impairments, as problems with concentration and understanding are less obvious than physical impairments and may have been under-reported.

11.5 Conclusion

This study aimed to answer seven research questions. These have been addressed as follows:

- The first two research questions were “What is the prevalence of disability in under-resourced areas in the Western Cape?” and “Is there a difference in the prevalence and pattern of disability between urban and semi-rural areas?”

Both areas presented with estimates higher than those from the national census (5.0-6.7%). The urban area of Nyanga presented with a disability prevalence of 13.1% and the semi-rural area of Oudtshoorn with a prevalence of 6.8%. Overall prevalence of disability rate was 9.7%. The types of impairment and functional limitations were similar in the two areas, but more severe disability was reported in the semi-rural area, that also had significantly more elderly people.

- What health conditions are related to disability and what is the “burden” due to disability for the most common conditions?

Non-communicable diseases were identified as the major cause of disability in both areas, followed by communicable diseases in Oudtshoorn and unintentional trauma in Nyanga. However, a person was twice as likely to be disabled due to non-communicable disease (OR 2.2) when living in Oudtshoorn, and three times more likely to be disabled due to intentional trauma when living in Nyanga (OR 0.3). Non-communicable diseases were responsible for the most healthy life years lost. Those living in Nyanga had a higher burden of disability due to their lower quality of life scores as measured by the EQ-5D.

- What is the impact of disability on function, i.e. what are the most common functional limitations? What is the relationship between disability domains and age?

Respondents in Nyanga consistently scored higher (worse) on all domains of the WHODAS-2 compared to respondents in Oudtshoorn. Living in Nyanga was associated with a 10% increase in domain scores. However, the pattern of scoring was similar and both areas reported worst functioning for the domains of Getting Around and Life Activities, which are associated with physical mobility. The largest difference in the mean ranking of the domains was seen in the Understanding and Getting Along domains. There was a weak but significant correlation between domain scores and age, but no gender differences were noted.

- What is the impact of disability on quality of life (QoL) and health-related quality of life (HRQoL) and does this differ between the two areas?

Respondents in Oudtshoorn reported better QoL and HRQoL than those in Nyanga. Functional level predicted the QoL scores, with Nyanga reporting worse functioning. Being employed and married was associated with a higher (better) EQ-5D VAS score, while mobility problems, pain or discomfort and anxiety or depression decreased the score. QoL scores were positively correlated with receiving medical rehabilitation.

- What environmental barriers and facilitators are experienced in the two areas? Is there a difference in disability profile between those who access services and those who do not? Do the urban and semi-rural areas differ?

Transport was the most commonly identified barrier in both areas. Major barriers for those living in Oudtshoorn were Surroundings and Help in the home, whereas Help in the home and Prejudice and discrimination were viewed as the major barriers for respondents in Nyanga. The elderly were the ones most likely to not receive the rehabilitation services that they needed. Access to rehabilitation impacted positively on perceived QoL.

The conclusions that can be drawn from this research is that context influences the experience of disability, and that disability prevalence alone is an insufficient basis for service planning. Those who experience greater deprivation also have a worse experience of disability. It is therefore essential for South Africa policy makers to view disability through a socio-political lens to ensure the equalisation of opportunities for people with disabilities. Improved quality of life for those living in under-resourced communities should be a priority. Service providers should have a broad range of skills to enable them to address not only the rehabilitation needs of people with disabilities, but also their social needs.

12 References

1. World Health Organization, World Bank: **World Report on Disability**. In. Geneva; 2011.
2. Mont D: **Measuring Disability Prevalence**. *The World Bank* 2007, **SP Discussion Paper**(No 0706).
3. Mont D, Loeb M: **Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities**. In. Edited by Labour SPa: World Bank; 2008.
4. Eide AH, Ingstad B: **Disability and Poverty: A Global Challenge**. Great Britain: The Policy Press; 2011.
5. Hosseinpoor AR, Williams JAS, Gautam J, Posarac A, Officer A, Verdes E, Kostanjsek N, Chatterji S: **Socioeconomic Inequality in Disability Among Adults: A Multicountry Study Using the World Health Survey**. *American Journal of Public Health* 2013, **103**(7):1278-1286.
6. **Census 2011 Statistical Release** [www.statssa.gov.za/Publications/P03014/P030142011.pdf]
7. Schneider M: **The difference a word makes: responding to questions on 'disability' and 'difficulty' in South Africa**. *Disability & Rehabilitation* 2009, **31**(1):42-50.
8. Lehohla P: **Census 2001: The Prevalence of Disability in South Africa**. 2005(03-02-44).
9. Statistics South Africa: **Achieving a Better Life for All: Progress Between Census '96 and Census 2001**. 2001.
10. Schneider M, Dasappa P, Khan N, Khan A: **Measuring disability in censuses: The case of South Africa**. *European Journal of Disability* 2009, **3**(3):245-265.
11. Statistics South Africa: **Community Survey, 2007 (Revised version)**. In.; 24 October 2007.
12. Madans J, Altman B, Rasch E, Mbogoni M, Banda J, Me A, DePalma E: **Washington Group Position Paper: Proposed Purpose of an Internationally Comparative General Disability Measure**. 2004.
13. Loeb M, Eide A, Mont D: **Approaching the measurement of disability prevalence: The case of Zambia**. *European Journal of Disability Research* 2008, **2**(1):32-43.
14. RAVIM & Handicap International Mozambique: **People with Disabilities in the Suburban Areas of Maputo and Matola**. In. Edited by Mozambique RHI; 2010.

15. Trani J-F, Bakshi P: **Challenges for assessing disability prevalence: The case of Afghanistan**. *Elsevier Masson SAS* 2008.
16. Household KC: **Africa's Burden of Disease: the University of Cape Town Sub-Saharan Africa Centre for Chronic Disease**. *SAMJ: South African Medical Journal* 2010, **100**:94-95.
17. Klijs B, Nusselder WJ, Looman CW, Mackenbach JP: **Contribution of Chronic Disease to the Burden of Disability**. *PLoS ONE* 2011, **6**(9):1-8.
18. Egede LE: **Diabetes, Major Depression, and Functional Disability Among U.S. Adults**. *Diabetes Care* 2004, **27**(2):421-428.
19. Berovich A: **People with disability in Brazil: a look at 2000 census results.** 2004.
20. **Prevalence and features of ICF-disability in Spain as captured by the 2008 National Disability Survey**. *BMC Public Health* 2011, **11**(1):897-911.
21. Statistics South Africa: **Mid-year population estimates**. In.; 2014.
22. Norman R, Matzopoulos R, Groenewald P, Bradshaw D: **The High Burden of Injuries in South Africa**. *Bulletin of the World Health Organization* 2007, **85**(9):649-732.
23. Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, Pieterse D, Schneider M, Bourne DE, Timaeus IM *et al*: **Initial Burden of Disease Estimates for South Africa, 2000: Original Article.** In: *SAMJ: South African Medical Journal.* vol. 93; 2003: 682-688.
24. **Adults with Disabilities: Physical activity is for everybody** [http://www.cdc.gov/vitalsigns/disabilities/]
25. Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA: **Health, preventive health care, and health care access among women with disabilities in the 1994-1995 National Health Interview Survey, Supplement on Disability**.
26. Trani J-F, Loeb M: **Poverty and disability: a vicious circle? Evidence from Afghanistand and Zambia.** *Journal of International Development* 2010.
27. Mitra S, Posarac A, Vick B: **Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey**. In.: Social Protection and Labour, World Bank; 2011.
28. Groce N, Kett M, Lang R, Trani J-F: **Disability and Poverty: the need for a more nuanced understanding of implications for development policy and practice**. *Third World Quarterly* 2011, **32**(8):1493-1513.
29. Braithwaite J, Mont D: **Disability and Poverty: A survey of World Bank Poverty Assessments and Implications**. In.: Social Protection and Labour: The World Bank 2008.

30. Adeyanju AB, Omisakin FD, Oyedele EA: **Health and Social Problems of Elderly People in Selected Areas of Ondo State, Nigeria**. *Indian Journal of Gerontology* 2014, **28**(2):231-243.
31. Statistics South Africa: **Census 2011 Census in brief.** In. Edited by Stats SA. Pretoria: Statistics South Africa; 2012.
32. M'Kumbuzi VRP, Sagahutu JB, Kagwiza J, Urimubenshi G, Mostert-Wentzel K: **The emerging pattern of disability in Rwanda**. *Disability & Rehabilitation* 2014, **36**(6):472-478.
33. United Nations: **Standard Rules for the Equalisation of Opportunities for Persons with Disabilities**. In. New York: UN; 1994.
34. United Nations: **Convention on the Rights of Persons with Disabilities and Optional Protocol**. 2008.
35. Office of the Deputy President T.M Mbeki: **White Paper on an Intergrated National Disability Strategy**. In.; November 1997.
36. Maart S, Jelsma J, Loeb M, Aide A, Ka Toni M: **Environmental barriers experienced by people with disabilities living in urban and rural communities in South Africa**. *Disability and Society* 2007, **22**(4):357-369.
37. Department of Health: **National Rehabilitation Policy**. In.; Nov 2000.
38. Western Cape Government **Healthcare 2030: The Road to Wellness**. In. Edited by Heath Do. Cape Town; March 2013.
39. WHO: **Health manpower requirements for the achievement of health for all by the year 2000 through primary health care**. In., vol. WHO Technical Report Series. Geneva: World Health Organisation; 1985.
40. Department of Health Western Cape: **Comprehensive Service Plan 2007**. In.; May 2007.
41. Kostanjsek N, Good A, Madden RH, Üstün TB, Chatterji S, Mathers CD, Officer A: **Counting disability: global and national estimation**. *Disability & Rehabilitation* 2013, **35**(13):1065-1069.
42. de Pedro-Cuesta J, Comin Comin M, Virues-Ortega J, Almazan Isla J, Avellanal F, Alcalde Cabero E, Burzaco O, Castellote J, Cieza A, Damian J *et al*: **ICF-based disability survey in a rural population of adults and older adults living in Cinco Villas (Northeastern Spain): Design, methods and population characteristics**. *Neuroepidemiology* 2010, **35**:72 - 82.

43. Rejeski WJ, Ip EH, Marsh AP, Miller ME, Farmer DF: **Measuring disability in older adults: The International Classification System of Functioning, Disability and Health (ICF) framework**. *Geriatrics & Gerontology International* 2008, **8**(1):48-54.

44. Leonardi M: **Measuring health and disability: supporting policy development. The European MHADIE project**. *Disability & Rehabilitation* 2010, **32**:S1-S8.

45. Srinivasan K, Vaz M, Thomas T: **Prevalence of health related disability among community dwelling urban elderly from middle socioeconomic strata in Bangaluru, India**. *Indian Journal of Medical Research* 2010, **131**(4):515-521.

46. Rimmer JH: **Use of the ICF in identifying factors that impact participation in physical activity/rehabilitation among people with disabilities**. In: *Disability & Rehabilitation.* vol. 28: Taylor & Francis Ltd; 2006: 1087-1095.

47. Loeb M, Eide A: **Living Conditions among People with Activity Limitations in Malawi. A National Representative Study.** In. Oslo: SINTEF; 2004.

48. Eide A, van Rooy G, Loeb M: **Living Conditions among People with Disabilities in Namibia. A National, Representative Study**. In. Oslo: SINTEF Unimed; 2003.

49. Madans JH, Loeb ME, Altman BM: **Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics**. *BMC Public Health* 2011, **11**(Suppl 4):1-8.

50. Chwastiak LA, Von Korff M: **Disability in depression and back pain: Evaluation of the World Health Organization Disability Assessment Schedule (WHO DAS II) in a primary care setting**. *Journal of Clinical Epidemiology* 2003, **56**(6):507-514.

51. Huq NL, Edmonds TJ, Baker SM, Busjia L, Devine A, Fotis K, Marella M, Goujon N, Keeffe JE: **The Rapid Assessment of Disability – Informing the Development of an Instrument to Measure the Effectiveness of Disability Inclusive Development Through a Qualitative Study in Bangladesh**. *2013* 2013, **24**(3):24.

52. McDermott S, Turk M: **The Myth and Reality of Disability Prevalence: Measuring Disability for Research and Service.** *Disability and Health Journal* 2011, **4**(1):1-5.

53. Murray CJL, Lopez AD: **Alternative Projections of Mortality and Disability by Cause 1990-2020: Global Burden of Disease Study**. *Lancet* 1997, **349**(9064):1498-1504.

54. Haines A, Horton R, Bhutta Z: **Primary health care comes of age. Looking forward to the 30th anniversary of Alma-Ata: call for papers**. *Lancet* 2007, **370**(9591):911-913.

55. Schneider H, Hlophe H, van Rensburg D: **Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects**. *Health Policy and Planning* 2008, **23**(3):179-187.

56. Expanded Public Works Programme Social Sector Plan 2004/5 - 2008/9: **EPWP- Social Sector**. In: *version 5 (240204).* Edited by Department of Social Development, Department of Education, Department of Health. Pretoria: South African Government; 2004.

57. Reynolds S: **Disability Culture in West Africa: Qualitative Research Indicating Barriers and Progress in the Greater Accra Region of Ghana**. *Occupational Therapy International* 2010, **17**(4):198-207.

58. Kleintjes S, Lund C, Swartz L: **Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: a qualitative study of perspectives of policy makers, professionals, religious leaders and academics**. *BMC International Health & Human Rights* 2013, **13**(1):17-26.

59. O'Brien K, Bayoumi A, Strike C, Young N, Davis A: **Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework**. *Health and quality of life outcomes* 2008, **6**(1):76.

60. Ricks TN, Harrison T: **Disability and Health: Exploring the Disablement Experience of Young Adult African Americans**. *Disability & Rehabilitation* 2014, **36**(6):479-486.

61. Bhagwanjee AM, Stewart R: **Disability research in South Africa:Vision and Imperatives for a national co-ordinated approach.** *South African Journal of Occupational Therapy* 1999, **29**(1):15-17.

62. Statistics South Africa: **Profile of Persons with Disabilities in South Africa**. In: *Census 2011- Disability Monograph.* 2014.

63. Jelsma J, Maart S, Eide AH, Toni M, Loeb M: **Who gets the disability grants in South Africa? An analysis of the characteristics of recipients in urban and rural areas.** *Disability & Rehabilitation: Assistive Technology* 2008, **30**(15):1139-1145.

64. Noble M, Babita M, Barnes H: **The Provincial Indices of Multiple Deprivation for South Africa 2001**. In.: HSRC and Statistics South Africa; 2006.

65. Townsend P: **Deprivation**. *Journal of Social Policy* 1987, **16**(2):125-146.

66. Noble M, Babita M, Barnes H, et al: **The Provincial Indices of Multiple Deprivation for South Africa 2001**. In.: HSRC and Statistics South Africa; 2006.

67. Wright G, Noble M: **The South African Index of Multiple Deprivation 2007 at Municipality Level**. In. Pretoria: Department of Social Development; 2009.

68. Municipality GO: **Integrated Development Planning 2007-2015**. In.; 2007/2008.

69. Statistics South Africa: **Census 2011- Municipal Report- Western Cape**. 2011, **Report 03-01-49**.

70. Ziehl SC: **Social and demographic trends, Western Cape, 2011**. In.; 2014.

71. City of Cape Town: **Regional Development Profile City of Cape Town**. In. Western Cape Government Provincial Treasury; 2011.
72. Njelesani J, Couto S, Cameron D: **Disability and rehabilitation in Tanzania: a review of the literature**. *Disability & Rehabilitation* 2011, **33**(23/24):2196-2207.
73. Hammell KW: **Quality of Life Among People with High Spinal Cord Injury Living in the Community**. *Spinal cord* 2004, **42**(11):607-620.
74. Oliver M, Alderson P: **Theories of disability in health practice and research**. *BMJ: British Medical Journal (International Edition)* 1998, **317**(7170):1446-1449.
75. Ngwena C: **Equality for People with Disabilities in the Workplace : an Overview of the Emergence of Disability as a Human Rights Issue**. In: *Journal for Juridical Science.* vol. 29; 2004: 167-197.
76. Schumm D, Stoltzfus M: **Chronic Illness and Disability: Narratives of Suffering and Healing in Buddhism and Christianity**. *Journal of Religion, Disability & Health* 2007, **11**(3):5-21.
77. Ingstad B: **The myth of disability in developing nations**. *Lancet* 1999, **354**(9180):757-758.
78. MacDonald R, Mullan Z, Horton R, Groce N, Shakespeare T, Officer A, Saxena S: **Bringing Disability off the Sidelines: a Call for Papers**. *Lancet* 2009, **373**(9669):1065-1066.
79. Coleridge P: **Disability, Liberation, and Development**: Oxfam; 1993.
80. Ingstad B, Whyte SR: **Disability and Culture**. Berkeley: University of California Press; 1995.
81. Swain J, French S: **Disability on equal terms**: Sage; 2008.
82. Amundson R: **Disability, Handicap, and the Environment**. *Journal of Social Philosophy* 1992, **23**(1):105-119.
83. Barnes C: **Institutional discrimination against disabled people and the campaign for anti- discrimination legislation**. *Critical Social Policy* 1992, **12**(34):5-22.
84. Nagi S: **Epidemiology of Disability among Adults in the United States**. *The Milbank Memorial Fund Quarterly Health and Society* 1976, **54**(4):439 - 467.
85. Nagi S: **Disability concepts revisited: implications for prevention**. *In: Disability in America: toward a national agenda for prevention* 1991.
86. Mont D: **Measuring health and disability**. *Lancet* 2007, **369**(9573):1658-1663.
87. Palmer M, Harley D: **Models and measurement in disability: an international review**. *Health Policy and Planning* 2011.

88. Thomas C: **How is disability understood? An examination of sociological approaches.** *Disability & Society* 2004, **19**:569-583.

89. Reindal SM: **Disability, Capability and Special Education: Towards a Capability-Based Approach**. *European Journal of Special Needs Education* 2008, **24**(2):155-168.

90. Groce NE: **Disability in Cross-Cultural Perspective: Rethinking Disability**. *Lancet* 1999, **354**(9180):755-757.

91. Kirby JC: **Disability and Justice: A Pluralistic Account**. *Social Theory & Practice* 2004, **30**(2):229-246.

92. De Bruijn C, de Bie R, Geraets J, Goossens M, van den Heuvel W, van der Heijden G, Candel M, Dinant G-J: **Effect of an Education and Activation Programme on Functional Limitations and Patient-Perceived Recovery in Acute and Sub-Acute Shoulder Complaints - a Randomised Clinical Trial**. *BMC Musculoskeletal Disorders* 2007, **8**:112-120.

93. McAuley E, Konopack JF, Morris KS, Moti RW, Liang H, Doerksen SE, Rosengren K: **Physical Activity and Functional Limitations in Older Women: Influence of Self-Efficacy**. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences* 2006, **61B**(5):270-P277.

94. Alderson P: **The Importance of Theories in Health Care**. *British Medical Journal* 1998, **317**(7164):1007-1010.

95. World Health Organization: **International Classification of Functioning, Disability and Health (ICF)**: Geneva: WHO Library Cataloguing-in-Publication Data; 2001.

96. Üstün TB, Chatterji S, Mechbal A, Murray CJL: **The World Health Surveys**. In: *Health Systems Performance Assessment: Debates, Methods and Empiricism.* Edited by Murray CJL, Evans DB. Geneva: World Health Organization; 2003: 797-808.

97. Swanson G, Carrothers L, Mulhorn K: **Comparing Disability Survey Questions in Five Countries: a Study using ICF to Guide Comparisons**. *Disability and Rehabilitation* 2003, **25**(11-12):665-675.

98. World Health Organization: **International Classification of Functioning, Disability and Health: ICF**. 2001.

99. Oliver M: **The politics of disablement: Critical texts in social work and the welfare state**. *London: Mac-Millan* 1990.

100. Bickenbach JE: **Physical disability and social policy**: University of Toronto Press Toronto; 1993.

101. Davis LJ: **Enforcing normalcy: Disability, deafness, and the body**: Verso; 1995.

102. Hurst R: **The international Disability Rights Movement and the ICF**. *Disability & Rehabilitation* 2003, **25**(11/12):572.

103. McDermott S, Turk MA: **The myth and reality of disability prevalence: measuring disability for research and service**. *Disability and Health Journal* 2011, **4**(1):1-5.

104. WHO: **Measuring health and disability: manual for WHO Disability Assessment Schedule (WHODAS 2.0)**. 2010.

105. United Nations: **United Nations General Assembly** In: *Resolution 37/52* 18 Feb 1982

106. Mannan H, McVeigh J, Amin M, MacLachlan M, Swartz L, Munthali A, Van Rooy G: **Core Concepts of Human Rights and Inclusion of Vulnerable Groups in the Disability and Rehabilitation Policies of Malawi, Namibia, Sudan, and South Africa**. *Journal of Disability Policy Studies* 2012, **23**(2):67-81.

107. Eide A, Ingstad B: **Disability and Poverty – Reflections on Research Experiences in Africa and Beyond**. *African Journal of Disability* 2012, **2**(1).

108. Baskind R, Birbeck GL: **Epilepsy-associated stigma in sub-Saharan Africa: The social landscape of a disease**. *Epilepsy & Behavior* 2005, **7**(1):68-73.

109. Loeb M, Eide A: **Paradigms lost: The changing face of disability in research**. *International views on disability measures: moving towards comparative measurement (Research in Social Science and Disability)* 2006, **4**:111 - 129.

110. Fujuira GT, Park HJ, Rutkowski-Kmitta V: **Disability Statistics in the Developing World: A Reflection on the meanings in our Numbers**. *Journal of Applied Research in Intellectual Disabilities* 2005, **18**:295-304.

111. Murray CJL, Lopez AD: **Measuring the Global Burden of Disease**. *New England Journal of Medicine* 2013, **369**(5):448-457.

112. Murray CJL, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, Ezzati M, Shibuya K, Salomon JA, Abdalla S *et al*: **Disability-Adjusted Life Years (DALYs) for 291 Diseases and Injuries in 21 Regions, 1990-2010: a Systematic Analysis for the Global Burden of Disease Study 2010**. *Lancet* 2012, **380**(9859):2197-2223.

113. World Health Organization: **World Health Survey 2002-2004**. In.; 2002-2004.

114. **WHO strategy focuses on simpler regimens and cheaper drugs**. *Lancet* 2003, **362**(9399):1901-1901.

115. Eide A, Kamaleri Y: **Living Conditions among People with Disabilities in Mozambique**. In. Oslo: SINTEF Health Research; 2009.

116. Loeb M, Eide A: **Living Conditions among People with Activity Limitations in Malawi: A National Representative Study.** In. Oslo: SINTEF Health Research; 2004.

117. Madans J, Loeb M, Altman B: **Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics**. *BMC Public Health* 2011, **11**(Suppl 4):S4.

118. Stone-MacDonald A: **Cultural Beliefs about Disability in Practice: Experiences at a Special School in Tanzania**. *International Journal of Disability, Development and Education* 2012, **59**(4):393-407.

119. Government of India: **Manual on Disability Statistics**. In. Edited by Implementation MoSaP. Sansad Marg, New Delhi: Central Statistics Office; 2012.

120. Meltzer H: **General measures of health for use in Health Interview surveys and Censuses: The UK Experience.** In. Presentation to Washington City Group meeting, Ottawa; 2003.

121. CASE Disability Survey: **We also Count! The Extent of Moderate and Severe Reported Disability and the Nature of the Disability Experience in South Africa.** In.; 1999.

122. Madden R, Fortune N, Cheeseman D, Mpofu E, Bundy A: **Fundamental questions before recording or measuring functioning and disability**. *Disability & Rehabilitation* 2013, **35**(13):1092-1096.

123. Bongani M Mayosi, Solomon R Benatar: **Health and Health Care in South Africa — 20 Years after Mandela**. *The New England Journal of Medicine* 2014, **14**(371):1344-1353.

124. Hanandita W, Tampubolon G: **Does poverty reduce mental health? An instrumental variable analysis**. *Social Science & Medicine* 2014, **113**:59-67.

125. Marengoni A, Angleman S, Fratiglioni L: **Prevalence of disability according to multimorbidity and disease clustering: a population-based study**. *2011* 2011, **1**(1):8.

126. Khandaker G, Muhit M, Rashid H, Khan A, Islam J, Jones C, Booy R: **Infectious Causes of Childhood Disability: Results from a Pilot Study in Rural Bangladesh**. *Journal of Tropical Pediatrics* 2014, **60**(5):363-369.

127. Idro R, Kakooza-Mwesige A, Balyejjussa S, Mirembe G, Mugasha C, Tugumisirize J, Byarugaba J: **Severe neurological sequelae and behaviourproblems after cerebral malaria in Ugandanchildren**. *BMC Research Notes* 2010, **3**:104-109.

128. Lansdown Gerison: **Disabled Children in South Africa Progress in implementing the Convention on theRights of the Child**. *The International Disability and Human Rights Network* 2002.

129. Murray CJL, Richards MA, Newton JN, Fenton KA, Anderson HR, Atkinson C, Bennett D, Bernabé E, Blencowe H, Bourne R *et al*: **UK Health Performance: Findings of the Global Burden of Disease Study 2010**. *Lancet* 2013, **381**(9871):997-1020.

130. Norman R, Matzopoulos R, Groenewald P, Bradshaw D: **The High Burden of Injuries in South Africa**. *Bulletin of the World Health Organization* 2007, **85**(9):695-702.

131. Dalal S, Beunza JJ, Volmink J, Adebamowo C, Bajunirwe F, Njelekela M, Mozaffarian D, Fawzi W, Willett W, Adami H-O *et al*: **Non-communicable diseases in sub-Saharan Africa: what we know now**. *International Journal of Epidemiology* 2011, **40**(4):885-901.

132. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D: **The Burden of Non-Communicable Diseases in South Africa**. *Lancet* 2009, **374**(9693):934-947.

133. Bertram MY, Jaswal AV, Van Wyk VP, Levitt NS, Hofman KJ: **The non-fatal disease burden caused by type 2 diabetes in South Africa, 2009**. *Glob Health Action* 2013, **6**(19244):19244.

134. Herman AA, Stein DJ, Seedat S, Heeringa SG, Moomal H, Williams DR: **The South African Stress and Health (SASH) Study: 12 Month and Lifetime Prevalence of Common Mental Disorders.** *SAMJ: South African Medical Journal* 2009, **99**:339-344.

135. Zheng X, Chen G, Song X, Liu J, Yan L, Du W, Pang L, Zhang L, Wu J, Zhang B *et al*: **Twenty-Year Trends in the Prevalence of Disability in China**. *Tendencias de la Prevalencia de Discapacidad en China a lo Largo de Veinte Años* 2011, **89**(11):788-797.

136. **4446.0-Disability, Australia, 2009**

137. Cambois E, Robine J-M, Romieu I: **The influence of functional limitations and various demographic factors on self-reported activity restriction at older ages**. *Disability & Rehabilitation* 2005, **27**(15):871-883.

138. Palacois-Ceña D, Jiménez-García R, Hernández-Barrera V, Alonso-Blanco C, Carrasco-Garrido P, Fernández-de-Las-Peñas C: **Has the Prevalence of Disability Increased over the Past Decade (2000-2007) in Elderly People? A Spanish Population-Based Survey.** *J MED DIR ASSOC* 2012, **13**(2):136-142.

139. Kempen G, van Heuvelen M, van Sonderen E: **The relationship of functional limitations to disability and the moderating effects of psychological attributes in community-dwelling older persons**. *Soc Sci Med* 1999, **48**:1161 - 1172.

140. Manton K, Stallard E, Corder L: **Changes in morbidity and chronic disability in the U.S elderly population: evidence from the 1982, 1984, and 1989 National Long Term Care Surveys.** *Journal of Gernotology: Social Sciences* 1995, **50B**(4):194-204.

141. Üstün TB, Sartorius N: **Mental Illness in General Health Care: an International Study**: John Wiley & Sons; 1995.

142. Demyttenaere K, Bruffaerts R, Posada-Villa J, Gasquet I, Kovess V, Lepine JP, Angermeyer MC, Bernert S, de Girolamo G, Morosini P *et al*: **Prevalence, Severity, and**

Unmet Need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys. *JAMA* 2004, **291**(21):2581-2590.

143. **International Classification of Functioning, Disability and Health**

144. Verbrugge L, Jette A: **The disablement process**. *Soc Sci Med* 1994, **38**:1 - 14.

145. Siegel J: **A generation of change: A profile of America's older population**. *New York: Russell Sage Foundation* 1993.

146. Koukouli S, Vlachonikolis I, Philalithis A: **Socio-demographic factors and self-reported funtional status: the significance of social support**. *BMC Health Services Research* 2002, **2**(1):20.

147. Phaswana-Mafuya N, Peltzer K, Chirinda W, Kose Z, Hoosain E, Ramlagan S, Tabane C, Davids A: **Self-rated health and associated factors among older South Africans: evidence from the study on global ageing and adult health**. *Global Health Action* 2013, **6**:1-10.

148. Almazán-Isla J, Comín-Comín M, Damián J, Alcalde-Cabero E, Ruiz C, Franco E, Martín G, Larrosa-Montañés LA, de Pedro-Cuesta J: **Analysis of disability using WHODAS 2.0 among the middle-aged and elderly in Cinco Villas, Spain**. *Disability and Health Journal*, **7**(1):78-87.

149. Merrill SS, Seeman TE, Kasl SV, Berkman LF: **Gender differences in the comparison of self-reported disability and performance measures**. *J Gerontol A Biol Sci Med Sci* 1997, **52**(1):M19-26.

150. Stevens GA, White RA, Flaxman SR, Price H, Jonas JB, Keeffe J, Leasher J, Naidoo K, Pesudovs K, Resnikoff S *et al*: **Global Prevalence of Vision Impairment and Blindness: Magnitude and Temporal Trends, 1990–2010**. *Ophthalmology* 2013, **120**(12):2377-2384.

151. Williams B, Copestake P, Eversley J, Stafford B: **Experiences and Expectations of Disabled People: A Research Report for the Office for Disability Issues**. In. Edited by Department for Work and Pensions. UK: Office for Disability Issues, HM Government 2008.

152. Garin O, Ayuso-Mateos JL, Almansa J, Nieto M, Chatterji S, Vilagut G, Alonso J, Cieza A, Svetskova O, Burger H *et al*: **Validation of the "World Health Organization Disability Assessment Schedule, WHODAS-2"**. *Health & Quality of Life Outcomes* 2010, **8**:51-65.

153. Grut L, Mji G, Braathen SH, Ingstad B: **Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa'**. *African Journal of Disability* 2012, **1**(1).

154. Benedicte Ingstadt and Susan Whyte: **Disability and Culture**. Berkeley: University of California Press; 1995.

155. Dube Andrew K: **The role and effectiveness of disability legislation in South Africa**. In: *Disability Knowledge and Research.* Edited by Stanley E; March 2005.

156. Gathiram N: **A critical review of the developmental approach to disability in South Africa**. *International Journal of Social Welfare* 2008, **17**(2):146-155.

157. Kinoshita Y, Furukawa TA, Kinoshita K, Honyashiki M, Omori IM, Marshall M, Bond GR, Huxley P, Amano N, Kingdon D: **Supported employment for adults with severe mental illness**. *Cochrane Database Syst Rev* 2013, **13**(9).

158. Gustafsson J, Peralta JP, Danermark B: **The employer's perspective on Supported employment for people with disabilities: Successful approaches of Supported employment organizations**. *Journal of Vocational Rehabilitation* 2013, **38**(2):99-111.

159. Waghorn G, Dias S, Gladman B, Harris M, Saha S: **A multi-site randomised controlled trial of evidence-based supported employment for adults with severe and persistent mental illness**. *Aust Occup Ther J* 2014, **4**(10):1440-1630.

160. Ronald Wiman, Einar Helander, Joan Westland: **Meeting the Needs of People with Disabilities—New Approaches in the Health Sector**. In: *A technical note.* June 2002.

161. Devi S, Goyal S, Ravindra S: **Evaluation of Environmental Barriers faced by Wheelchair Users in India**. *2013* 2013, **24**(3):14.

162. Sheldon A: **Women and disability**. In: *Disabling barriers–enabling environments.* edn. Edited by John Swain, Sally French, Colin Barnes, Thomas C. London: Sage; 2004: 69-74.

163. Deegan MJ, Brooks NA: **Women and Disability: The Double Handicap**: Transaction Publishers.

164. Shipway L: **Domestic Violence: A Handbook for Health Care Professionals**: Routledge; 2004.

165. Guyatt GH, Feeny DH, Patrick DL: **Measuring Health-Related Quality of Life**. *Annals of Internal Medicine* 1993, **118**(8):622-629.

166. Huber JG, Sillick J, Skarakis-Doyle E: **Personal perception and personal factors: incorporating health-related quality of life into the International Classification of Functioning, Disability and Health**. *Disability & Rehabilitation* 2010, **32**(23):1955-1965.

167. Jelsma J, Ramma L: **How do children at special schools and their parents perceive their HRQoL compared to children at open schools?** *Health and Quality of Life Outcomes* 2010, **8**(1):72.

168. Chappell NL, Cooke HA: **Age Related Disabilities - Aging and Quality of Life**. In: *International Encyclopedia of Rehabilitation.* Edited by JH Stone MB; 2010.

169. Liang W-M, Chen J-J, Chang C-H, Chen H-W, Chen S-L, Hang L-W, Wang J-D: **An Empirical Comparison of the WHOQOL-BREF and the SGRQ among Patients with COPD**. *Quality of Life Research* 2008, **17**(5):793-800.

170. Donmez L, Gokkoca Z, Dedeoglu N: **Disability and its effects on quality of life among older people living in Antalya city center, Turkey**. *Arch Gerontol Geriatr* 2005, **40**:213 - 223.

171. Nyirenda M, Newell M-L, Mugisha J, Mutevedzi PC, Seeley J, Scholten F, Kowal P: **Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa**. *Global Health Action* 2013.

172. Mattevi B, Bredemeier J, Fam C, Fleck M: **Quality of care, quality of life, and attitudes toward disabilities: perspectives from a qualitative focus group study in Porto Alegre**. *Brazil Rev Panam Salud Publ* 2012, **31**(3):188 - 196.

173. Maart S: **Identifying the domains used by Afrikaans speaking people in describing their health-related quality of life**. 2004.

174. Jelsma J, Mkoka S, Amosun SL: **Health-related quality of life (HRQoL) domains most valued by urban isiXhosa-speaking people**. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2008, **17**(1):137-145.

175. Lustig DC, David RS: **Causal Relationships Between Poverty and Disability**. *Rehabilitation Counseling Bulletin* 2007, **50**(4):194-202.

176. Palmer M: **Disability and Poverty: A Conceptual Review**. *Journal of Disability Policy Studies* 2011, **21**(4):210-218.

177. Mitra S, Posarac A, Vick B: **Disability and Poverty in Developing Countries: A Multidimensional Study**. *World Development* 2013, **41**:1-18.

178. Klasen S: **MEASURING POVERTY AND DEPRIVATION IN SOUTH AFRICA**. *Review of Income and Wealth* 2000, **46**(1):33-58.

179. de Hollander AEM, Staatsen BAM: **Health, environment and quality of life: an epidemiological perspective on urban development**. *Landscape and Urban Planning* 2003, **65**(1–2):53-62.

180. von Schirnding Y, Yach D: **Environmental health impacts associated with rapid urbanisation in South Africa**. *Public Health Rev* 1991, **19**(1-4):295-302.

181. Peer N, Steyn K, Lombard C, Lambert EV, Vythilingum B, Levitt NS: **Rising Diabetes Prevalence among Urban-Dwelling Black South Africans**. *PLoS ONE* 2012, **7**(9):e43336.

182. Williams ED, Tillin T, Whincup P, Forouhi NG, Chaturvedi N, Baradaran HR: **Ethnic Differences in Disability Prevalence and Their Determinants Studied over a 20-Year Period: A Cohort Study**. *PLoS ONE* 2012, **7**(9):1-8.

183. Noble M, Babita M, Barnes H, Dibben C, Magasela W, Noble S, Ntshongwana P, Phillips H, Rama S, Roberts B *et al*: **The Provincial Indices of Multiple Deprivation for South Africa 2001.** In.; 2001.

184. Disler PB, Jacka E, Sayed AR, Rip MR, Hurford S, Collis P: **The prevalence of locomotor disability and handicap in the Cape Peninsula. Part III. The white population of Fish Hoek**. *S Afr Med J* 1986, **69**(6):355-357.

185. Bless C, Higson-Smith C: **Fundementals of Social Research Methods-An African Perspective**, Second Edition edn. Cape Town, South Africa: Juta and Co, Ltd; 1995.

186. Bland JM, Altman DG: **Statistical methods for assessing agreement between two methods of clinical measurement**. *Lancet* 1986, **1**(8476):307-310.

187. Raykov T: **Alpha if item deleted: A note on loss of criterion validity in scale development if maximizing coefficient alpha**. *British Journal of Mathematical & Statistical Psychology* 2008, **61**(2):275-285.

188. Tavakol M, Reg D: **Making Sense of Cronbach's Alpha**. *International Journal of Medical Education* 2011, **2**:53-55.

189. Kimberlin CL, Winterstein AG: **Validity and Reliability of Measurement Instruments used in Research**. *Am J Health Syst Pharm* 2008, **65**(23):2276-2284.

190. Roberts P, Priest H, Traynor M: **Reliability and validity in research**. *Nursing Standard* 2006, **20**(44):41-45.

191. Twycross A, Shields L: **Validity and reliability - What's it all about?** *Paediatric Nursing* 2004, **16**(9):28-28.

192. Leedy PD: **Practical Research: Planning and Design**, Fourth Edition edn. United States of America: Macmillan Publishing Company; 1989.

193. Graham JW, Collins NL: **Controlling Correlational Bias via Confirmatory Factor Analysis of MTMM Data**. *Multivariate Behavioral Research* 1991, **26**(4):607.

194. Madans JH, Loeb M: **Methods to Improve International Comparability of Census and Survey Measures of Disability**. *Disability & Rehabilitation* 2013, **35**(13):1070-1073.

195. Eide AH, Loeb ME: **Data and Statistics on Disability in Developing Countries**. *Disability Knowledge and Research* 2005.

196. Washington Group: **Proposed Pets for Measuring Disability: 8th WG Meeting, Manila, Philippines**. In., vol. (Version 1: 17 October, 2008); 29 – 30 October 2008.

197. Üstün TB, Chatterji S, Kostanjsek N, Rehm J, Kennedy C, Epping-Jordan J, Saxena S, von Korff M, Pull C: **Developing the World Health Organization Disability Assessment Schedule 2.0**. *Bulletin of the World Health Organization* 2010, **88**(11):815-823.

198. Perenboom RJM, Chorus AMJ: **Measuring participation according to the International Classification of Functioning, Disability and Health (ICF)**. *Disability and Rehabilitation* 2003, **25**(11-12):577-587.

199. Üstün TB, Kostanjsek N, Chatterji JR, Rehm J: **Measuring Health and Disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0**. In. Malta: World Health Organisation; 2010.

200. Gallagher P, Mulvany F: **Levels of ability and functioning: using the WHODAS II in an Irish context**. *Disability and Rehabilitation* 2004, **26**(9):506-517.

201. Sousa RM, Dewey ME, Acosta D, Jotheeswaran AT, Castro-Costa E, Ferri CP, Guerra M, Huang Y, Jacob KS, Pichardo JGR *et al*: **Measuring disability across cultures — the psychometric properties of the WHODAS II in older people from seven low- and middle-income countries. The 10/66 Dementia Research Group population-based survey**. *International Journal of Methods in Psychiatric Research* 2010, **19**(1):1-17.

202. Hu L, Zang Y-l, Li N: **The applicability of WHODAS 2.0 in adolescents in China**. *Journal of Clinical Nursing* 2012, **21**(17/18):2438-2451.

203. McKibbin C, Patterson T, Jeste D: **Assessing disability in older patients with schizophrenia: results from the WHODAS-II**. *J Nerv Ment Dis* 2004, **192**:405 - 413.

204. Noonan V, Kopec J, Noreau L, Singer J, Mâsse L, Zhang H, Dvorak M: **Measuring Participation Among Persons with Spinal Cord Injury: Comparison of Three Instruments**. *Topics in Spinal Cord Injury Rehabilitation* 2010, **15**(4):49-62.

205. Küçükdeveci AA, Kutlay Ş, Yıldızlar D, Öztuna D, Elhan AH, Tennant A: **The reliability and validity of the World Health Organization Disability Assessment Schedule (WHODAS-II) in stroke**. *Disability and Rehabilitation* 2013, **35**(3):214-220.

206. Meesters JJL, Verhoef J, Liem ISL, Putter H, Vliet Vlieland TPM: **Validity and responsiveness of the World Health Organization Disability Assessment Schedule II to assess disability in rheumatoid arthritis patients**. *Rheumatology* 2010, **49**(2):326-333.

207. Peltzer K, Phaswana-Mafuya N: **Levels of ability and functioning of persons living with HIV and AIDS using the WHO DAS II in a South African context**. *J Soc Dev Afr* 2008, **23**(2):33 - 53.

208. Zhao H, Liu Y, Li H, Ma L, Zhang Y, Wang J: **Activity limitation and participation restrictions of breast cancer patients receiving chemotherapy: psychometric**

properties and validation of the Chinese version of the WHODAS 2.0. *Quality of Life Research* 2013, **22**(4):897-906.

209. Wolf AC TR, Lannin NA, Middleton J, Lane-Brown A, Cameron ID.: **The World Health Organization Disability Assessment Scale, WHODAS II: Reliability and Validity in the Measurement of Activity and Participation in a Spinal Cord Injury Population**. *J Rehabil Med* 2012, **44**(9):747-755. doi: 710.2340/16501977-16501016.

210. Kutlay S, Kucukdeveci AA, Elhan AH, Oztuna D, Koc N, Tennant A: **Validation of the World Health Organization disability assessment schedule II (WHODAS-II) in patients with osteoarthritis**. *Rheumatol Int* 2011, **31**(3):339-346.

211. The WHOQOL Group: **The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization**. *Social Science & Medicine* 1995, **41**(10):1403-1409.

212. Skevington SM, Lotfy M, O'Connell KA: **The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group**. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2004, **13**(2):299-310.

213. Colbourn T, Masache G, Skordis-Worrall J: **Development, reliability and validity of the Chichewa WHOQOL-BREF in adults in lilongwe, Malawi**. *BMC Research Notes* 2012, **5**(1):346.

214. Gómez-Olivé FX, Thorogood M, Clark B, Kahn K, Tollman S: **Self-reported health and health care use in an ageing population in the Agincourt sub-district of rural South Africa**. *Global Health Action* 2013.

215. Nedjat S, Montazeri A, Holakouie K, Mohammad K, Majdzadeh R: **Psychometric properties of the Iranian interview-administered version of the World Health Organization's Quality of Life Questionnaire (WHOQOL-BREF): A population-based study**. *BMC Heal Serv Res* 2008, **8**(6):1.

216. Hanestad B, Rustoen T, Knudsen O, Lerdal A, Wahl A: **Psychometric properties of the WHOQOL-BREF questionnaire for the Norwegian general population**. *J Nurs Meas* 2004, **12**(2):147 - 159.

217. Jaracz K, Kalfoss M, Gorna K, Baczyk G: **Quality of life in Polish respondents: psychometric properties of the Polish WHOQOL--Bref**. *Scand J Caring Sci* 2006, **20**:251 - 260.

218. Taylor WJ, Myers J, Simpson RT, McPherson KM, Weatherall M: **Quality of life of people with rheumatoid arthritis as measured by the World Health Organization**

Quality of Life Instrument, short form (WHOQOL-BREF): score distributions and psychometric properties. *Arthritis Rheum* 2004, **51**(3):350-357.

219. da Silva Lima AF, Fleck M, Pechansky F, de Boni R, Sukop P: **Psychometric properties of the World Health Organization quality of life instrument (WHOQoL-BREF) in alcoholic males: a pilot study**. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2005, **14**(2):473-478.
220. Sakthong P, Schommer JC, Gross CR, Sakulbumrungsil R, Prasithsirikul W: **Psychometric properties of WHOQOL-BREF-THAI in patients with HIV/AIDS**. *J Med Assoc Thai* 2007, **90**(11):2449-2460.
221. Chiu WT, Huang SJ, Hwang HF, Tsauo JY, Chen CF, Tsai SH, Lin MR: **Use of the WHOQOL-BREF for evaluating persons with traumatic brain injury**. *J Neurotrauma* 2006, **23**(11):1609-1620.
222. Webster J, Nicholas C, Velacott C, Cridland N, Fawcett L: **Validation of the WHOQOL-BREF among women following childbirth**. *Aust N Z J Obstet Gynaecol* 2010, **50**:132 - 137.
223. Castro Mda G, Oliveira Mda S, Miguel AC, Araujo RB: **WHOQOL-BREF psychometric properties in a sample of smokers**. *Rev Bras Psiquiatr* 2007, **29**(3):254-257.
224. Huang IC, Wu AW, Frangakis C: **Do the SF-36 and WHOQOL-BREF measure the same constructs? Evidence from the Taiwan population***. *Qual Life Res* 2006, **15**(1):15-24.
225. Gusi N, Olivares PR, Rajendram R: **The EQ-5D Health-Related Quality of Life Questionnaire**. In: *Handbook of Disease Burdens and Quality of Life Measures.* edn. Edited by Preedy V, Watson R: Springer New York; 2010: 87-99.
226. Gold M, Russell L, Siegel J, Weinstein M: New York: Oxford University Press; 1996.
227. Drummond M, Sculpher M, Torrance G, O'Brien B, Stoddart G: New York: Oxford University Press; 2005.
228. Myers C, Wilks D: **Comparison of Euroqol EQ-5D and SF-36 in Patients with Chronic Fatigue Syndrome**. *Quality of Life Research* 1999, **8**(1/2):9-16.
229. Huang I, Willke R, Atkinson M, Lenderking W, franngakis C, Wu A: **US and UK versions of the EQ-5D preference weights: Dose choice of preference weights make a difference?** *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2007, **16**:1065 - 1072.
230. Picavet HSJ, Hoeymans N: **Health related quality of life in multiple musculoskeletal diseases: SF-36 and EQ-5D in the DMC3 study**. *Annals of the Rheumatic Diseases* 2004, **63**(6):723-729.

231. Jelsma J, Mkoka S, Amosun L, Nieuwveldt J: **The reliability and validity of the Xhosa version of the EQ-5D**. *Disabil Rehabil* 2004, **26**(2):103-108.

232. Mkoka S, Vaughan J, Wylie T, Yelland H, Jelsma J: **The pitfalls of translation--a case study based on the translation of the EQ-5D into Xhosa**. *S Afr Med J* 2003, **93**(4):265-266.

233. Galway LP, Bell N, Al Shatari SAE, Hagopian A, Burnham G, Flaxman A, Weiss W, Rajaratnam J, Takaro T: **A Two-Stage Cluster Sampling Method using Gridded Population Data, a GIS, and Google EarthTM Imagery in a Population-Based Mortality Survey in Iraq**. *International Journal of Health Geographics* 2012, **11**(1):12.

234. Skinner CJ: **Design Effects of Two-Stage Sampling**. *Journal of the Royal Statistical Society Series B (Methodological)* 1986, **48**(1):89-99.

235. Gulliford MC, Ukoumunne OC, Chinn S: **Components of Variance and Intraclass Correlations for the Design of Community-based Surveys and Intervention Studies: Data from the Health Survey for England 1994**. *American Journal of Epidemiology* 1999, **149**(9):876-883.

236. Statistics South Africa: **Census 2001 Stats in Brief**. In.; 2001.

237. Dolan P: **Modeling valuations for EuroQol health states**. *Medical Care* 1997, **35**(11):1095-1108.

238. The WHOQOL Group: **Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group**. *Psychol Med* 1998, **28**(3):551-558.

239. Aberson CL, Berger DE, Healy MR, Kyle DJ, Romero VL: **Evaluation of an interactive tutorial for teaching the central limit theorem**. *Teaching of Psychology* 2000, **27**(4):289-291.

240. Pillay-van Wyk V, Msemburi W, Laubscher R, Dorrington RE, Groenewald P, Matzopoulos R, Prinsloo M, Nojilana B, Nannan N, Gwebushe N *et al*: **Second National Burden of Disease Study South Africa: National and Subnational Mortality Trends, 1997-2009**. *Lancet* 2013, **381**:S113.

241. Palmer M, Harley D: **Models and measurement in disability: an international review.** *Health Policy and Planning* 2012, **27**(5):357-364.

242. Washington Group on Disability Statistics: **Report of the Twelfth meeting: 23-25 October 2012 in Bangkok, Thailand** In.; 2012.

243. Ataguba A, Akazili J, McIntyre D: **Socioeconomic-related health inequality in South Africa: evidence from General Household Surveys**. *International Journal of Equity in Health* 2011, **10**(48).

244. Disler PB, Jacka E, Sayed AR, Rip MR, Hurford S, Collis P: **The prevalence of locomotor disability and handicap in the Cape Peninsula. Part II. The black population of Nyanga**. *South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde* 1986, **69**(6):353-355.

245. Karlsen S, Nazroo J: **Religious and Ethnic differences in health: evidence from the Health Surveys for England 1999 to 2004.** *Ethnicity and Health* 2010, **15**(6).

246. Fuller-Thompson E, Nuru-Jeter A, Minkler M, Guralnik JM: **Black-White disparities in disability among older Americans: further untangling the role of race and socio-economic status**. *Journal of Ageing and Health* 2009, **21**:677-698.

247. Ethgen O, Gillain D, Gillet P, Gosset C, Jousten A, Reginster J: **Age and Sex Stratified Prevalence of Physical Disabilities and Handicap in the General Population.** *Aging Clin EXP* 2004, **16**(5):389-397.

248. GBD 2010 Country Collaboration: **GBD 2010 Country Results: a Global Public Good**. *Lancet* 2013, **381**(9871):965-970.

249. Peeters G, Dobson A, Deeg D, Brown W: **A Life-Course Perspective on Physical Functioning in Women.** *Bulletin of the World Health Organization* 2013, **91**:661-670.

250. Parahyba MI, Stevens K, Henley W, Lang LA, Melzer D: **Reductions in Disability Prevalence Among the Highest Income Groups of Older Brazilians**. *American Journal of Public Health* 2009, **99**(1):81-86.

251. Disler PB, Jacka E, Sayed AR, Rip MR, Hurford S, Collis P: **The prevalence of locomotor disability and handicap in the Cape Peninsula. Part I. The coloured population of Bishop Lavis**. *S Afr Med J* 1986, **69**(6):349-352.

252. Evers R: **Urban migrants: A focus on their social networks and vulnerability dynamic. The case of Eastern Cape migrants in Port Elizabeth, and Cape Town, South Africa.** Nijmegen: Radboud University; 2012.

253. Ustun TB: **The World Health Surveys**. In: *Health Systems Performance Assessment: Debates, Methods and Empiricism.* Edited by Murray CJL, Evans DB. Geneva: WHO; 2003.

254. Helander E: **Prejudice and Dignity. An Introduction to Community-based Rehabilitation**: United Nations Development Programme; 1992.

255. Andresen EM, Vahle VJ, Lollar D: **Proxy reliability: health-related quality of life (HRQoL) measures for people with disability**. *Quality of Life Research* 2001, **10**(7):609-619.

256. Molton I, Cook KF, Smith AE, Amtmann D, Chen WH, Jensen MP: **Prevalence and impact of pain in adults aging with a physical disability: comparison to a US general population sample**. *Clin J Pain* 2014, **30**(4):307-315.

257. Vearey J: **Sampling in an Urban Environment: Overcoming Complexities and Capturing Differences**. *Journal of Refugee Studies* 2012.

258. Peeters G, Dobson AJ, Deeg DJH, Brown WJ: **A life-course perspective on physical functioning in women.** *Bull World Health Organ* 2013, **91**:661-670.

259. World Health Organization: **National Institute on Aging National Institutes of Health**. In.; October 2011.

260. World Health Organization: **Global Health and Aging**. In. Edited by National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services, vol. NIH Publication no. 11-7737; October 2011.

261. Hairi NN, Bulgiba A, Cumming RG, Naganathan V, Mudla I: **Prevalence and Correlates of Physical Disability and Functional Limitation Among Community Dwelling Older People in Rural Malaysia, a Middle Income Country**. *BMC Public Health* 2010, **10**:492-504.

262. Avlund K, Rantanen T, Schroll M: **Tiredness and Subsequent Disability in Older Adults: The Role of Walking Limitations**. *The Journals of Gerontology Series A, Biological Sciences and Medical Sciences* 2006, **61**(11):1201-1205.

263. Urwin M, Symmons D, Allison T, Brammah T, Busby H, Roxby M, Simmons A, Williams G: **Estimating the Burden of Musculoskeletal Disorders in the Community: the Comparative Prevalence of Symptoms at Different Anatomical Sites, and the Relation to Social Deprivation**. *Annals of the Rheumatic Diseases* 1998, **57**:649-655.

264. Nash ES, Meiring PD: **The coloured elderly in Cape Town--a psychosocial, psychiatric and medical community survey. Part III. A survey of physical disorders and disabilities**. *S Afr Med J* 1983, **64**(28):1089-1094.

265. Ntsoane MD, Oduntan OA, Mpolokeng BL: **Utilisation of public eye care services by the rural community residents in the Capricorn district, Limpopo Province, South Africa**, vol. 4; 2012.

266. Department of Health Republic of South Africa: **A District Hospital Service Package for South Africa: A set of norms and standards**. In.; May 2002.

267. Rotchford AP, Rotchford KM, Mthethwa LP, Johnson GJ: **Reasons for Poor Cataract Surgery Uptake - a Qualitative Study in Rural South Africa**. *Trop Med Int Health* 2002, **7**(3):288-292.

268. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D: **Health in South Africa 4. The burden of non-communicable diseases in South Africa**. *Lancet* 2009, **374**(9693):934-947.

269. Mathers C, Boerma T, Ma Fat D: **The Global Burden of Disease: 2004 Update.** In. Geneva: World Health Organisation Press; 2008.

270. Anakwenze U, Zuberi D: **Mental Health and Poverty in the Inner City**. *Health & Social Work* 2013, **38**(3):147-157.

271. De Cock KM, Simone PM, Davison V, Slutsker L: **The New Global Health**. *Emerging Infectious Diseases* 2013, **19**(8):1192-1197.

272. Department of Health: **The Primary Health Care Package for South Africa – a set of norms and standards Part 1 Norms and standards for health clinics Part 2 Norms and standards for community based clinic initiated services**. In. Pretoria; 2000.

273. Steyn K, Lombard C, Gwebushe N, Fourie JM, Everett-Murphy K, Zwarenstein M, Levitt NS: **Implementation of National Guidelines, Incorporated within Structured Diabetes and Hypertension Records at Primary Level Care in Cape Town, South Africa: a Randomised Controlled Trial**. *Global Health Action* 2013, **6**:20796.

274. Myers J, Naledi T: **Western Cape Burden of Disease Reduction Project**. In., vol. Vol 1-7; 2007.

275. National Department of Health South Africa: **Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17**. In.; 2013.

276. Bergmo TS: **Using QALYs in telehealth evaluations: a systematic review of methodology and transparency**. *BMC Health Serv Res* 2014, **14**:332.

277. Brooks R: **EuroQol: the current state of play**. *Health policy* 1996, **37**(1):53-72.

278. Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, Pieterse D, Schneider M, Bourne DE, Timaeus IM *et al*: **Initial burden of disease estimates for South Africa, 2000 : original article**. In., vol. 93; 2003: p.682-688.

279. Reddy KS, Yusuf S: **Emerging Epidemic of Cardiovascular Disease in Developing Countries**. *Circulation* 1998, **97**(6):596-601.

280. World Health Organization: **Diet, Nutrition, and the Prevention of Chronic Diseases**. In. Edited by Report of a Joint WHO/FAO Expert Consultation, vol. WHO Technical Report Series 916. Geneva.; 2003.

281. Kengne AP, Mayosi BM: **Readiness of the primary care system for non-communicable diseases in sub-Saharan Africa**. *The Lancet Global Health* 2014, **2**(5):e247-e248.

282. Krisela Steyn, Jean Fourie, Norman Temple: **Chronic Diseases of Lifestyle in South Africa:1995-2005**. Cape Town; 2006.

283. de-Graft Aikins A, Boynton P, Atanga L: **Developing effective chronic disease interventions in Africa: insights from Ghana and Cameroon**. *Globalization and Health* 2010, **6**(1):6.

284. Vorster HH, Venter CS, Wissing MP, Margetts BM: **The nutrition and health transition in the North West Province of South Africa: a review of the THUSA (Transition and Health during Urbanisation of South Africans) study**. *Public Health Nutr* 2005, **8**(5):480-490.

285. Friel S, Chopra M, Satcher D: **Unequal weight: equity oriented policy responses to the global obesity epidemic**. *BMJ* 2007, **335**(7632):1241-1243.

286. Martens P: **Health transitions in a globalising world: towards more disease or sustained health?** *Futures* 2002, **34**(7):635-648.

287. Solarsh G, Hofman K: **Developmental Disabilities.** In: *Disease and Mortality in Sub-Saharan Africa.* Edited by Jamison D, Feachem R, Makgoba M, et al. Washinton DC: World Bank; 2006.

288. Horton R: **GBD 2010: Understanding Disease, Injury, and Risk**. *Lancet* 2012, **380**(9859):2053-2054.

289. Attar SM: **Musculoskeletal Manifestations in Diabetic Patients at a Tertiary Center**. *Libyan Journal of Medicine* 2012, **7**.

290. Brad J. Bushman, Roy F. Baumeister: **Threatened Egotism, Narcissism, Self-Esteem, and Direct and Displaced Aggression: Does Self-Love or Self-Hate Lead to Violence?** *Journal of Personality and Social Psychology* 1998, **75**(1):219-229.

291. Donnelan M, Trzesniewski K, Robins R, Moffit T and Caspi A: **Low Self Esteem is Related to Aggression, Anti-Social Behaviour and Deliquency**. *Psychological Science* 2005, **16**(No 4):328-335.

292. OECD: **OECD Economic Surveys SOUTH AFRICA**. In.: www.oecd.org/eco/surveys/southafrica.

293. Saul R, Phillips D: **Ghosts and Germs: Cerebral Palsy in Nepal—a Preliminary Exploration of Cosmology and Disability**. Leeds, UK: Disability Press; 1999.

294. Onya H: **Health Promotion in South Africa**. *Promotion & Education* 2007, **14**(4):233-237.

295. Üstün T, Kostanjsek N, Chatterji S, Rehm J: **Measuring Health and Disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0**. In. Malta: World Health Organization; 2010.

296. Chopra P, Couper J, Herrman H: **The Assessment of Patients with Long-Term Psychotic Disorders: Application of the WHO Disability Assessment Schedule II**. *Aust N Z J Psychiatry* 2004, **38**:753 - 759.

297. Garin O, Ayuso-Mateos J, Almansa J, Nieto M, Chatterji S, Vilagut G, Alonso J, Cieza A, Svetskova O, Burger H *et al*: **Validation of the "World Health Organization Disability Assessment Schedule, WHODAS-2" in Patients with Chronic Diseases**. *Health and Quality of Life Outcomes* 2010, **8**(1):51.

298. van Tubergen A, Landewe R, Heuft-Dorenbosch L, Spoorenberg A, van der Heijden D, van der Tempel H, van der Linden S: **Assessment of Disability with the World Health Organisation Disability Assessment Schedule II in Patients with Ankylosing Spondylitis**. *Ann Rheum Dis* 2003, **62**:140 - 145.

299. Von Korff M, Crane PK, Alonso J, Vilagut G, Angermeyer MC, Bruffaerts R, de Girolamo G, Gureje O, de Graaf R, Huang Y *et al*: **Modified WHODAS-II provides valid measure of global disability but filter items increased skewness**. *Journal of Clinical Epidemiology* 2008, **61**(11):1132-1143.

300. Karvonen-Gutierrez CA, Ylitalo KR: **Prevalence and Correlates of Disability in a Late Middle-Aged Population of Women**. *Journal of Aging and Health* 2013, **25**(4):701-717.

301. Chang K-H, Lin Y-N, Liao H-F, Yen C-F, Escorpizo R, Yen T-H, Liou T-H: **Environmental effects on WHODAS 2.0 among patients with stroke with a focus on ICF category e120**. *Quality of Life Research* 2014, **23**(6):1823-1831.

302. Andrews G, Kemp A, Sunderland M, Von Korff M, Ustun TB: **Normative Data for the 12 Item WHO Disability Assessment Schedule 2.0**. *PLoS ONE* 2009, **4**(12):e8343.

303. Hoffman M, Pick W, Joubert G, Yach D, Thomas T, Klopper JM: **Morbidity profile of the Mamre community**. *S Afr Med J* 1988, **74**(7):358-361.

304. Edwards B, O'Connell B: **Internal consistency and validity of the Stroke Impact Scale 2.0 (SIS 2.0) and SIS-16 in an Australian sample**. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2003, **12**(8):1127-1135.

305. Xia P, Li N, Hau KT, Liu C, Lu Y: **Quality of life of Chinese urban community residents: a psychometric study of the mainland Chinese version of the WHOQOL-BREF**. *BMC medical research methodology* 2012, **12**:37.

306. Oldreive W, Waight M: **Enabling access to information by people with learning disabilities**. *Tizard Learning Disability Review* 2013, **18**(1):5-15.

307. Williamson K, Schauder D, Stockfield L, Wright S, Bow A: **The role of the internet for people with disabilities: issues of access and equity for public**. *Australian Library Journal* 2001, **50**(2):157.

308. Mates BT: **INFORMATION ACCESS FOR PEOPLE WITH DISABILITIES**. *Library Technology Reports* 2004, **40**(3):10-31.

309. Jelsma J, Ferguson G: **The determinants of self-reported health-related quality of life in a culturally and socially diverse South African community**. *Bulletin of the World Health Organisation* 2004, **82**(3):206-212.

310. Jelsma J, Mkoka S, Amosun L, Nieuwveldt J: **The reliability and validity of the Xhosa version of the EQ-5D**. *Disability and rehabilitation* 2004, **26**(2):103-108.

311. Abdin E, Subramaniam M, Vaingankar JA, Luo N, Chong SA: **Measuring health-related quality of life among adults in Singapore: population norms for the EQ-5D**. *Quality of Life Research* 2013, **10**:2983-2991.

312. Hwang HF, Liang WM, Chiu YN, Lin MR: **Suitability of the WHOQOL-BREF for community-dwelling older people in Taiwan**. *Age Ageing* 2003, **32**(6):593-600.

313. Nyirenda M, Chatterji S, Falkingham J, Mutevedzi P, Hosegood V, Evandrou M, Kowal P, Newell M-L: **An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa**. *BMC Public Health* 2012, **12**(1):259.

314. Joubert J, Bradshaw D: **Population ageing and health challenges in South Africa**. *Chronic Diseases of Lifestyle in South Africa: 1995-2005* 2006.

315. Xavier Gomez-Olive F, Thorogood M, Clark B, Kahn K, Tollman S: **Assessing health and well-being among older people in rural South Africa**. *Global Health Action* 2010, **3**(Supplt 2):23 - 35.

316. Wolinsky FD, Coe RM, Miller DK, Prendergast JM: **Correlates of change in subjective well-being among the elderly**. *J Community Health* 1985, **10**(2):93-107.

317. Kotze H: **Status of Disability Rights in Southern Africa**. *Open Society Initiative for Southern Africa* 2012, **05**.

318. Herdman M, Fox-Rushby J, Badia X: **A Model of Equivalence in the Cultural Adaptation of HRQoL Instruments: the Universalist Approach**. *Quality of Life Research* 1998, **7**(4):323-335.

319. Beaton DE, Bombardier C, Guillemin F, Ferraz MB: **Guidelines for the process of cross-cultural adaptation of self-report measures**. *Spine* 1976, **25**(24):3186-3191.

320. Cronbach L: **Coefficient alpha and the internal structure of tests**. *Psychometrika* 1951, **16**:297 - 334.

321. Hsiung PC, Fang CT, Chang YY, Chen MY, Wang JD: **Comparison of WHOQOL-bREF and SF-36 in patients with HIV infection**. *Quality of Life Research* 2005, **14**(1):141-150.

322. Huang I, Wu A, Frangakis C: **Do the SF-36 and WHOQOL-BREF Measure the Same Constructs? Evidence from the Taiwan Population**. *Quality of Life Research* 2006, **15**:15 - 24.

323. Trompenaars FJ, Masthoff ED, Van Heck GL, Hodiamont PP, De Vries J: **Content Validity, Construct Validity, and Reliability of the WHOQOL-Bref in a Population of Dutch Adult Psychiatric Outpatients**. *Quality of Life Research* 2005, **14**(1):151-160.

324. Thomas C, Narahari SR, Bose KS, Vivekananda K, Nwe S, West DP, Kwasny M, Kundu RV: **Comparison of Three Quality of Life Instruments in Lymphatic Filariasis: DLQI, WHODAS 2.0, and LFSQQ**. *PLoS Negl Trop Dis* 2014, **8**(2):1-8.

325. Pösl M, Cieza A, Stucki G: **Psychometric Properties of the WHODASII in Rehabilitation Patients**. *Quality of Life Research* 2007, **16**(9):1521-1531.

326. Küçükdeveci AA, Kutlay Ş, Yıldızlar D, Öztuna D, Elhan AH, Tennant A: **The Reliability and Validity of the World Health Organization Disability Assessment Schedule (WHODAS-II) in Stroke**. *Disability & Rehabilitation* 2013, **35**(3):214-220.

327. Federici S, Meloni F, Mancini A, Lauriola M, Olivetti Belardinelli M: **World Health Organisation Disability Assessment Schedule II: Contribution to the Italian validation**. *Disability & Rehabilitation* 2009, **31**(7):553-564.

328. Skevington SM, Lotfy M, O'Connell KA: **The World Health Organization's WHOQOL-BREF Quality of Life Assessment: Psychometric Properties and Results of the International Field Trial. A Report from the WHOQOL Group**. *Quality of Life Research* 2004, **13**(2):299-310.

329. Streiner DL: **Starting and beginning: an introduction to coefficient alpha and internal consistency** *Journal of Personality Assessment* 2003, **80**:99-103.

330. Chwastiak LA, Von Korff M: **Disability in Depression and Back Pain: Evaluation of the World Health Organization Disability Assessment Schedule (WHO DAS II) in a Primary Care Setting**. *Journal of Clinical Epidemiology* 2003, **56**(6):507-514.

331. Nedjat S, Montazeri A, Holakouie K, Mohammad K, Majdzadeh R: **Psychometric properties of the Iranian interview-administered version of the World Health Organization's Quality of Life Questionnaire (WHOQOL-BREF): A population-based study**. *BMC Health Services Research* 2008, **8**(1):61.

332. Usefy AR, Ghassemi GR, Sarrafzadegan N, Mallik S, Baghaei AM, Rabiei K: **Psychometric Properties of the WHOQOL-BREF in an Iranian Adult Sample**. *Community Mental Health Journal* 2010, **46**(2):139-147.

333. Chung W-S, Lan Y-L, Yang M-C: **Psychometric Testing of the Short Version of the World Health Organization Quality of Life (WHOQOL-BREF) Questionnaire among Pulmonary Tuberculosis Patients in Taiwan**. *BMC Public Health* 2012, **12**(1):630-639.

334. Statistics South Africa: **Census 2011 Statistical Release**. In: *PO03014.* 2011.

335. Zunzunegui M, Nunez O, Durban M, Garcia de Yebenes M, Otero A: **Decreasing prevalence of disability in activities of daily living, functional limitations and poor self-rated health: a 6-year follow-up study in Spain**. *Aging Clin Exp Res* 2006, **18**:352 - 358.

336. Hoeymans N, Wong A, Gool CHv, Deeg DJH, Nusselder WJ, de Klerk MMY, van Boxtel MPJ, Picavet HSJ: **The Disabling Effect of Diseases: A Study on Trends in Diseases, Activity Limitations, and Their Interrelationships**. *American Journal of Public Health* 2012, **102**(1):163-170.

337. Palacois-Ceña D J-GR, Hernández-Barrera V, Alonso-Blanco C, Carrasco-Garrido P, Fernández-de-Las-Peñas C: **Has the prevalence of disability increased over the past decade (2000-2007) in elderly people? A Spanish population-based survey.** *J MED DIR ASSOC* 2013.

338. Mayosi B, Flisher A, Lalloo U, Sitas F, Tollman S, Bradshaw D: **The burden of non-communicable diseases in South Africa**. *Lancet* 2009, **374**(9693):934 - 947.

339. Mensah G, Mayosi B: **The 2011 United Nations High-Level Meeting on Non-Communicable Diseases: The Africa agenda calls for a 5-by-5 approach.** *SAMJ: South African Medical Journal* 2012, **103**(2):77-79.

340. McKenzie K: **Urbanization, Social Capital and Mental Health**. *La Urbanización, el Capital Social y la Salud Mental* 2008, **8**(3):359-377.

341. Trivedi JK, Sareen H, Dhyani M: **Rapid urbanization - Its impact on mental health: A South Asian perspective**. *Indian Journal of Psychiatry* 2008, **50**(3):161-165.

342. Harpham T, Stephens C: **Urbanization and health in developing countries**. *World Health Stat Q* 1991, **44**(2):62-69.

343. **City of Cape Town – 2011 Census Suburb Nyanga** [http://www.capetown.gov.za/en/stats/2011CensusSuburbs/2011_Census_CT_Suburb_Nyanga_Profile.pdf]

344. **White Paper on an Integrated National Disability Strategy**. In. Edited by Mbeki OotDPTM; November 1997.

13 Appendices

Participant information and consent sheet

South African Survey of

Quality of Life in Disabled Individuals

Participant Information Sheet (for Screening Questionnaire)

WHAT ARE WE TRYING TO DO?

We are researchers from the University of Cape Town and we are interested in finding out in what ways having some sort of disability. makes a difference to a person's life. We want to answer questions such as do people who have disabilities have more problems with education and getting work? Do people with disabilities have more problems in being part of the family and taking part in community activities? We also want to know how many people there are with disabilities and what problems they have with moving around and doing things.

WHY HAVE WE CONTACTED YOU?

In order to answer these questions we are interviewing 2000 households to find people with disabilities to find out how many people there are with these problems. Your house has been randomly selected from an aerial map, to include in our sample of households.

WHAT WILL YOU BE ASKED TO DO?

The field workers will interview you and fill in a questionnaire that will assist in the identification of a person with disability.

Each interview will take about 45 minutes. We know that this is a long time but we want to get as much information as possible.

WHAT WILL YOU GET IF YOU TAKE PART?

There is no payment or reward for taking part in the study and there is no reason for you to take part unless you would like to help us understand the situation of people with disabilities better.

We will make all the information known (but not your name or address) to the local authorities, to the local institutions that provide assistance to people with disabilities and to provincial and central government. We hope that what we find might lead to changes being made, but we cannot promise this. In the short term there will be no direct benefit to you or your family.

Nothing bad will happen to you if you do not want to take part. Even if you do take part, you can stop answering questions at any time and you can refuse to answer specific questions.

If you would like them to do so, the field assistants will refer people who take part to whatever services they need which may be available in the area.

ARE THERE ANY RISKS TO TAKING PART?

There are no risks, except you might feel sad when talking about your problems.

WILL PEOPLE KNOW WHAT ANSWERS YOU HAVE GIVEN?

All the answers will be put together and no-one will know who gave any specific answer except the researchers and maybe members of the Ethics Committee of the University of Cape Town (which is a committee that makes sure that people who take part in research are protected). Your name will not be given to anyone and will not be listed anywhere. The results of the project will be made available to organisations of disabled people, local and government authorities and the scientific community but no names will be linked to any results.

WHO CAN I ASK ABOUT THIS STUDY ?

Your participation would be greatly appreciated. Should you have any questions please contact one of the researchers Soraya Maart on 0832843364. Alternatively you may contact the Human Ethics Committee in room E52-24 Groote Schuur Hospital Old Main Building or phone 021-406 6338.

CONSENT

I confirm that the study has been explained to me, and that I had the opportunity to ask questions.

I confirm that I have received the study information sheet (SASDIQ information sheet for participants) and that I understand its contents.

I understand that my participation is voluntary and that refusal to participate will not affect me in any negative way.

I understand that I can refuse to answer any question that I do not wish to answer and that I can stop the interview if I do not wish to continue.

I understand that any information that I provide will be kept confidential. I understand that when the results of the study will be published and presented, all my personal details will be made anonymous and that I will never be identified in any of these publications or presentations.

I understand that this study may be followed by other studies in the future.

- ○ I agree to be contacted in order to receive information about any study related to this research in future. I understand that after receiving information about future studies I am free to decide whether or not I wish to participate in these future studies.
- ○ I do not wish to be contacted about any future study.

(please cross one of the above answers)

I .....(Name) the undersigned, consent to participate in this study.

Signature :..... Date:.....

Witness:..... Date:.....

South African Survey of
Quality of Life in Disabled Individuals

Information sheet for those identified as having a disability

WHAT ARE WE TRYING TO DO?

We are researchers from the University of Cape Town and we are interested in finding out in what ways having some sort of disability

makes a difference to a person's life. We want to answer questions such as do people who have disabilities have more problems with education and getting work? Do people with disabilities have more problems in being part of the family and taking part in community activities? We also want to know how many people there are with disabilities and what problems they have with moving around and doing things.

WHY HAVE WE CONTACTED YOU?

In order to answer these questions we interviewed 2000 households to find people with disabilities to find out how many people there are with these problems. Your family member said that you might have a problem like this. So we would like to interview you to see what type of problems you are having

WHAT WILL YOU BE ASKED TO DO?

The field workers will interview you and fill in quite a few questionnaires. Some of the questionnaires are about your quality of life and how healthy and happy you feel. Others are about how the disability makes a difference to what you can do and how other people help and support you.

Each interview will take about 45 minutes. We know that this is a long time but we want to get as much information as possible so that we can better understand the problems that you face.

WHAT WILL YOU GET IF YOU TAKE PART?

There is no payment or reward for taking part in the study and there is no reason for you to take part unless you would like to help us understand the situation of people with disabilities and better.

We will make all the information known (but not your name or address) to the local authorities, to the local institutions that provide assistance to people with disabilities and to provincial and central government. We hope that what we find might lead to changes being made, but we cannot promise this. In the short term there will be no direct benefit to you or your family.

Nothing bad will happen to you if you do not want to take part. Even if you do take part, you can stop answering questions at any time and you can refuse to answer specific questions.
If you would like them to do so, the field assistants will refer people who take part to whatever services they need which may be available in the area.

ARE THERE ANY RISKS TO TAKING PART?

There are no risks, except you might feel sad when talking about your problems.

WILL PEOPLE KNOW WHAT ANSWERS YOU HAVE GIVEN?

All the answers will be put together and no-one will know who gave any specific answer except the researchers and maybe members of the Ethics Committee of the University of Cape Town (which is a committee that makes sure that people who take part in research are protected). Your name will not be given to anyone and will not be listed anywhere. The results of the project will be made available to organisations of disabled people, local and government authorities and the scientific community but no names will be linked to any results.

Your participation would be greatly appreciated. Should you have any questions please contact: Soraya Maart on 083284336

CONSENT

I confirm that the study has been explained to me, and that I had the opportunity to ask questions.
I confirm that I have received the study information sheet (SASDIQ information sheet for participants) and that I understand its contents.

I understand that my participation is voluntary and that refusal to participate will not affect me in any negative way.

I understand that I can refuse to answer any question that I do not wish to answer and that I can stop the interview if I do not wish to continue.

I understand that any information that I provide will be kept confidential. I understand that when the results of the study will be published and presented, all my personal details will be made anonymous and that I will never be identified in any of these publications or presentations.

I understand that this study may be followed by other studies in the future.

- ○ I agree to be contacted in order to receive information about any study related to this research in future. I understand that after receiving information about future studies I am free to decide whether or not I wish to participate in these future studies.
- ○ I do not wish to be contacted about any future study.

(please cross one of the above answers)

I .....(Name) the undersigned, consent to participate in this study.

Signature :..... Date:.....

Witness:..... Date:.....

South African Survey of
Quality of Life in Disabled Individuals

Participant Consent Form: Assessment of Health-related Quality of Life

1. I confirm that the study has been explained to me, and that I had the opportunity to ask questions.
2. I confirm that I have received the study information sheet (SASQID information sheet for participants) and that I understand its contents.
3. I understand that my participation is voluntary and that refusal to participate will not affect me in any negative way.
4. I understand that I can refuse to answer any question that I do not wish to answer and that I can stop the interview if I do not wish to continue.
5. I understand that any information that I provide will be kept confidential. I understand that when the results of the study will be published and presented, all my personal details will be made anonymous and that I will never be identified in any of these publications or presentations.
6. I understand that this study may be followed by other studies in the future.
   - ○ I agree to be contacted in order to receive information about any study related to this research in future. I understand that after receiving information about future studies I am free to decide whether or not I wish to participate in these future studies.
   - ○ I do not wish to be contacted about any future study.

   (please cross one of the above answers)

I .....(Name)

the undersigned, consent to participate in this study.

Signature :.....

Date:.....

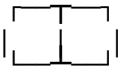
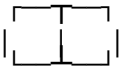
Witness:.....

Date:.....

DEMOGRAPHIC AND SCREENING QUESTIONNAIRE

IDENTIFICATION OF HOUSEHOLD	
NAME OF STREET _____	☐☐
NAME OF AREA _____	
HOUSEHOLD NUMBER ……..	
NAME OF HOUSEHOLD HEAD _____	☐☐☐
INTERVIEW STATUS [1 = Completed; 2 = Partly completed; 3 = Refused; 4 = Not at home]	☐
DATE OF FIRST VISIT: DAY __ __ MONTH __ __ YEAR 2011	☐☐
TOTAL NUMBER OF PERSONS IN HOUSEHOLD (should be the same as last Line Number filled in Section A)	☐
TOTAL NUMBER OF DISABLED PERSONS (sum of column 7)	☐☐
TOTAL NUMBER OF INFERTILE PERSONS (sum of column 9)	☐☐
)	☐☐
LINE NO. OF PRIMARY RESPONDENT	

TO BE COMPLETED BY INTERVIEWER TIME INTERVIEW: STARTED _____ COMPLETED _____ NAME OF INTERVIEWER _____ SIGNATURE _____	DATE OF INTERVIEW DAY ☐☐ MONTH ☐☐ YEAR ☐☐☐☐ 2 0 1 1

SUPERVISOR	INTERVIEWER	KEYED BY
NAME _____  SIGNATURE _____		

* CODES FOR REGION:
01 = 02 =

Type of Household (Circle one)	
CASE	CONTROL

HOUSEHOLD COMPOSITION: FOR ALL PERSONS

LINE NO.	1. WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD	2. RELATIONSHIP TO HEAD OF HOUSEHOLD	3. 14 SEX	4. AGE	5. MARITAL STATUS	15 6. 16 DISABILITY SCREENING (Based on Activity Limitations)	7. 17 ELIGIBILITY Circle the line number of:	8. Fertility screening	18 9. 19 ELIGIBILITY Circle the line number of:

	List the first names and first letter of the surname of all persons in this household, starting with the head of the household.	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female? 1=Male 2=Female	How old was (NAME) at his/her last birthday ? Enter age in completed years 98=Don't know	What is (NAME'S) marital status? **	Does (NAME) ever have any difficulties in: 1. seeing , even when wearing glasses 2. hearing, even if using a hearing aid 3. walking or climbing steps 4. remembering or concentrating 5. With self care such as washing all over or dressing 6. using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others) **1=No, no difficulty** **2=Yes, some difficulty** **3=yes, a lot of difficulty** **4= cannot do it at all**	Has this difficulty lasted, or is it expected to last 6 months or more? 1=Yes 2=No 8=Don't know	Does (NAME) need assistance to do day-to-day activities? 1=Yes, A lot 2=Yes, A little 3=No 8=Don't know	All Persons With a disability	Has (NAME) been trying with the same partner to have a baby for the last 12 months without the woman falling pregnant? 1=yes 2=no 3=don't know (Enter only one code)	1=Females 21-45 years 2=Males 21 and older

(1)		(2)	(3)	(4)	(5)	(6)	(6B)	(6C)	(7)	(8)	(9)
01		01	M F 1 2	IN YEARS					01		
02			1 2						02		
03			1 2						03		
04			1 2						04		
05			1 2						05		
06			1 2						06		
07			1 2						07		

08			1 2						08		
09			1 2						09		
10			1 2						10		

***CODES FOR Q.2**
RELATIONSHIP TO HEAD OF HOUSEHOLD:

01 = Head
02 = Husband/wife
03 = Son/Daughter
04 = Son/Daughter-in-law
05 = Grandchild of head/spouse
06 = Parent of head/spouse
07 = Brother/Sister of head/spouse
08 = Other relative
09 = Domestic worker/Non-relative
10 = Other non-relatives
98 = Don't know

****CODES FOR Q6**
MARITAL STATUS

1 = Never married
2 = Married with certificate
3 = Married traditional
4 = Consensual union
5 = Divorced/separated
6 = Widowed
7 = Other (specify)
8 = Don't know

B. LEVEL OF EDUCATION OF HOUSEHOLD MEMBERS – AGED 5 YEARS OR ABOVE

LINE NO.	**10. SCHOOL AGE**	**11. SCHOOL ATTENDANCE**	**12. REASONS FOR LEAVING/DROPPING OUT OF SCHOOL OR COLLEGE**		**13. HIGHEST GRADE COMPLETED**
	Is (NAME) 5 years or older? 1=Yes 2=No	Has (NAME) attended any school/college? 1=Never attended **(go to (14A))** **If YES,** 2=Still attending 3=Left school/ college 8=Don't know	If (NAME) left school, why? 0=Finished school 1=Not enough money 2=Failing/underachiever 3=Illness 4=Lack of interest 5=Because of disability 6=School not accessible 7=Pregnancy 8=Other (specify) 9=Don't know **(Code up to 2 reasons)**		What is (NAME'S) highest standard, form or level of education completed? * 98 = Don't know
	(10)	(11)	(12)	(12B)	(13)
01	YESNO 1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
02	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
03	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
04	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
05	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
06	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘
07	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐¬⌐¬ └┘└┘

08	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐T¬ └┴┘
09	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐T¬ └┴┘
10	1 2	⌐¬ └┘	⌐¬ └┘	⌐¬ └┘	⌐T¬ └┴┘

***CODES FOR Q.13**

20 HIGHEST GRADE COMPLETED

00 = not completed Sub A/Grade 1 01 = Sub A / Grade 1
02 = Sub B / Grade 2
03 = Std. 1 / Grade 3
04 = Std. 2 / Grade 4
05 = Std. 3 / Grade 5
06 = Std. 4 / Grade 6
07 = Std. 5 / Grade 7
08 = Std. 6 / Grade 8
09 = Std. 7 / Grade 9
10 = Std. 8 / Grade 10
11 = Std 9. / Grade 11
12 = Std. 10 / Grade 12
13 = Diploma, Certificate or Degree
14 = Post Graduates

98 = Don't know

**** CODES FOR Q. 14 & 15: LANGUAGES**

1 = Xhosa
2 = Afrikaans
3 = English
4 = Zulu
5 = Other (specify)
6 = Sign Language

9 = Don't know

C. ECONOMIC ACTIVITY OF HOUSEHOLD MEMBERS AGED 15 YEARS OR ABOVE

LINE NO.	**14.PERMANENT MEMBERS OF THE HOUSEHOLD**	**15.CURRENT WORK STATUS**	**16.TYPE OF WORK**	**17.**
	Transfer from Section (A) the line number and names of the permanent household members who are aged 15 years or above.	Is (NAME) currently working for pay, profit or family gain? 1=Yes, currently working 2= No, not currently working	What kind of work did (NAME) spend most of his/her time on? (If the person engages in more than one economic activity, ask on which job he/she spends most of his/her working time and describe that one/name that job title, i.e. describe only the current main job)	Does (NAME) work full time or part time? 1=Full time 2=Part time /casual labour
	(14)	(15)	(16)	(17)
		⌐¬ └┘		1 2

				1 2
				1 2
				1 2
				1 2
				1 2
				1 2
				1 2
				1 2
				1 2
				1 2
				1 2

NOTE: To be completed by the PRIMARY RESPONDENT identified on the cover page

E: INCOME

18. Household total monthly income

Income may be seasonal, for example dependent on the sale of farm produce. For that reason we'd like to know:

What is the household's total income (from ALL members) from ALL sources during a GOOD and during a BAD month? State the exact amount **or** use the Income Category.
If the income is unknown, circle '99'. If the household does not have an income, circle '0' (None).

Amount or Category	(a) Good month income	(b) Bad month income
State exact amount in SA Rand	⌐¬⌐¬⌐¬⌐¬⌐¬⌐¬⌐¬ | | | | | | | | └┴┘└┴┘└┴┘└┴┘└┴┘└┴┘└┴┘	⌐¬⌐¬⌐¬⌐¬⌐¬⌐¬⌐¬ | | | | | | | | └┴┘└┴┘└┴┘└┴┘└┴┘└┴┘└┴┘
Or use Income Category. (Circle only **one** answer for each column)		
None	0	0
<1000	1	1
1000-2999	2	2
3000-4999	3	3
5000-6999	4	4
7000-8999	5	5
9000-10999	6	6
11000-12999	7	7
13000-14999	8	8
15000-16999	9	9
>=17000	10	10
Unknown	99	99

19. From the list below, indicate only the main or primary source of income.

If "Not stated/Refused" circle 99.

Income Category	Primary source (Circle only **one**)
a. Wage/Salary work (Gross salary)	01
b. Formal business (registered)	07
c. Informal business (non-registered: see Manual)	08
d. Private insurance/pension	09
e. Workman's Compensation	10
f. Rent	11
g. Others (specify)	12
h. No income from any source	13
i. Not stated/Refused	99

BURDEN OF DISEASE IN THE FAMILY

20. Has any household member been chronically ill during the past twelve months? (See list of diseases

listed in column 6 below) (Circle only one)

21 Yes	1
No	2
Don't know	8

21. If YES, could you please tell me:

	What is the ill person's relationship to the household head? 0 Head 1 Spouse 2 Son/Daughter of head/spouse 3 Spouse of child 4 Grandchild of head/spouse 5 Parent of head/spouse 6 Other relative 7 Domestic worker/non-relative 8 Other non-relatives 9 Don't know (Enter only one code)	**Is the ill person female or male?** 1 Male 2 Female (Enter 1 code)	**How old is she/he?** For children who were aged less than one year (11 months or less), enter the age in months in column (4). For persons who were 1 year or older, enter that age in years in column (5).		**Could you tell me what the illness is/was?** 01 Cancer 02 TB 03 Malaria 04 Diarrhoea 05 Malnutrition 06 Measles 07 Pneumonia 08 Heart disease 09 High blood pressure 10 HIV/AIDS (related) 11 Diabetes 12 Other disease (specify) 99 Don't know (Enter only one code)
			less than 1 year (Enter number in months)	**one year or older (Enter number in years)**	
(1)	**(2)**	**(3)**	**(4)**	**(5)**	**(6)**
Person 1					
Person 2					
Person 3					
Person 4					
Person 5					
Person 6					

EQ-5D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about	❑
I have some problems in walking about	❑
I am confined to bed	❑

Self-Care

I have no problems with self-care	❑
I have some problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑
I have some problems with performing my usual activities	❑
I am unable to perform my usual activities	❑

Pain/Discomfort

I have no pain or discomfort	❑
I have moderate pain or discomfort	❑
I have extreme pain or discomfort	❑

Anxiety/Depression

I am not anxious or depressed	❑
I am moderately anxious or depressed	❑
I am extremely anxious or depressed	❑

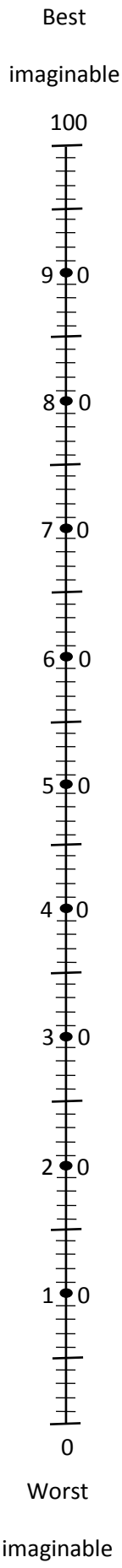
Compared with my general
level of health over the past 12 months,
my health state today is:

Better	❑	PLEASE TICK
Much the same	❑	ONE
Worse	❑	BOX

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state



WHOQOL-BREF

Instructions

This questionnaire asks how you feel about your quality of life, health and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

	(Please circle the number)				
	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
How would you rate your quality of life?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your health?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
To what extent do you feel that physical pain prevents you from doing what you need to do?	**1**	**2**	**3**	**4**	**5**
How much do you need any medical treatment to function in your daily life?	**1**	**2**	**3**	**4**	**5**
How much do you enjoy life?	**1**	**2**	**3**	**4**	**5**

		(Please circle the number)			
	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
To what extent do you feel you life to be meaningful?	**1**	**2**	**3**	**4**	**5**
How well are you able to concentrate?	**1**	**2**	**3**	**4**	**5**
How safe do you feel in your daily life?	**1**	**2**	**3**	**4**	**5**
How healthy is your physical environment?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
Do you have enough energy for everyday life?	**1**	**2**	**3**	**4**	**5**
Are you able to accept your bodily appearance?	**1**	**2**	**3**	**4**	**5**
Have you enough money to meet your needs?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
How available to you is the information that you need in your day-to-day life?	**1**	**2**	**3**	**4**	**5**
To what extent do you have the opportunity for leisure activities?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Very poor	**Poor**	**Neither poor nor well**	**Well**	**Very well**
How well are you able to get around?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your sleep?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your ability to perform your daily living activities?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your capacity for work?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
How satisfied are you with your abilities	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your personal relationships?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your sex life?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with the support you get from your friends?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with the conditions of your living place?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your access to health services?	**1**	**2**	**3**	**4**	**5**
How satisfied are you with your mode of transportation?	**1**	**2**	**3**	**4**	**5**

	(Please circle the number)				
	Never	**Seldom**	**Quite often**	**Very often**	**Always**
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	**1**	**2**	**3**	**4**	**5**

Did someone help you to fill out this form? (Please circle yes or no) Yes No

How long did it take to fill out this form? _____

END OF INTERVIEW

THANK RESPONDENT AND CLOSE INTERVIEW. MENTION THAT ANOTHER INTERVIEWER MIGHT COME TO DO A BRIEF CHECK ON THE QUESTIONNAIRE

Impact of Disability Questionnaire

IMPACT OF DISABILITY QUESTIONNAIRES

IDENTIFICATION OF PERSON WITH DISABILITY

IDENTIFICATION OF PERSON WITH DISABILITY

STREET ADDRESS _____

_____

NAME OF AREA

_____

HOUSEHOLD NUMBER

……..

NAME OF HOUSEHOLD HEAD

_____

NAME AND LINE NUMBER OF
PERSON WITH DISABILITY

_____

AGE OF PERSON WITH DISABILITY……

IS THE PERSON REPORTING THE PERSON WITH DISABILITY? [Do not read out. Code by observation]

1 Yes

2 No (i.e. someone else is reporting for the person with disability)

IF **NO**, WHO IS THE PERSON REPORTING?
NAME AND LINE NUMBER OF PERSON

_____

Date of visit: Day: __ __ Month __ __ Year 2011

Time Started: _____ Time Completed: _____

INTERVIEW STATUS [1 = Completed; 2 = Partly completed; 3 = Refused; 4 = Not at home]

Date of Interview: Day: __ __ Month: __ __ Year: 2011

IDENTIFICATION OF PERSON WITH DISABILITY	
DATE OF RETURN VISIT (IF REQUIRED): Day: __ __ Month: __ __ Year: 2011	

SUPERVISOR	INTERVIEWER	Data entered by
NAME _____ ___ SIGNATURE _____		

* CODES FOR REGION: 01 = 02 = 03 =

LET'S TALK ABOUT YOUR DISABILITY.

INSTRUCTION: ASK BOTH DIRECT & PROXY RESPONDENTS

Please describe your disability as it is without the use of assistive devices or any person helping you.
(Write down what respondent says in their own words.)

_____

_____

_____

_____

_____

Describe the service/assistance that would improve your current situation

(Write down what respondent says in their own words.)

_____

_____

_____

_____

What caused your disability?

[Write down what respondent says in their own words.]

How old were you when it started?

[Write down what respondent says in their own words.]

Have you ever lived in an institution or special home for people with disabilities?

Yes	1
No	2
Don't know	8

SERVICES YOU ARE AWARE OF AND HAVE NEEDED AND/OR RECEIVED FOR YOUR DISABILITY (like

health, rehabilitation, welfare & other such services).

Which services, if any, are you *aware* of and have ever *needed/received*?

[Read out; Enter the appropriate code for each column of each row]

	Aware of service 1=Yes 2=No	Needed service 1=Yes 2=No	Received service 1=Yes 2=No
	(1)	(2)	(3)
a. Medical rehabilitation (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)			
b. Assistive devices service (e.g. from an orthopaedic workshop, wheelchair, hearing/visual aids, Braille etc.)			
c. Educational services (e.g. remedial therapist, special school, early childhood stimulation, regular schooling, etc.)			
d. Vocational training (e.g. employment skills training, etc)			
e. Counselling for person with disability (e.g. psychologist, psychiatrist, social worker, school counsellor etc)			
f. Counselling for parent/family			
g. Welfare services (e.g. social worker, disability grant, etc)			
h. Health services (e.g. at a primary health care clinic, hospital, home health care services etc.)			
i. Traditional healer/faith healer			
j. Home-based care			
k. Community development worker			

If no services received, i.e. all 2 = ”No” for column (3) above, then go to Section 4.

What problems, if any have you experienced with services in the past? (Think of ALL services

received) *[Circle ALL that apply] Do not read out.*

	Yes	No
a. No more money/too expensive	1	2
b. Too far/no transport	1	2
c. Not helping anymore/no improvement	1	2
d. Reached level of functioning I/we set as goal	1	2
e. Services were no longer available	1	2
f. Not satisfied with services	1	2
g. Communication/language barrier	1	2
h. Other (specify) _____	1	2

Do you receive a disability grant or any other form of grant or pension?

Yes	1
No	2
Don't know	8

What type of grant or pension is it?

[Do not read out; circle all that apply. Enter amount per month OR lump sum]

Type of grant or pension	Code (1)	Amount per month (2)	Lump sum (3)
a. Disability grant	1		
b. Other grant (e.g. Care-giver, Child grant etc.)	2		
c. Workman's Compensation	3		

d. Private insurance/pension	4		
e. Old age pension	5		
f. Other (specify) _____	6		
g. Don't know	8		
TOTAL AMOUNT			

ONLY ASK DISABLED RESPONDENTS WHO ARE 15 YEARS OF AGE OR OLDER AND REPORTING FOR THEMSELVES.

IF THE RESPONDENT IS A PROXY REPORTER FOR A PERSON WITH DISABILITY 15 YEARS OR OLDER, THEN ASK THEM TO ANSWER ABOUT THE PERSON WITH DISABILITY.

Circle one answer	YES	NO
Is the person with disability 15 years of age or older?	1	2

Are you married or involved in a relationship?

Yes	1
No	2
Don't know	8

Does your spouse/partner have a disability?

Yes	1

No	2
Don't know	8

Do you have children?

Yes	1
No	2

If Yes, how many?

Children

Who MAINLY takes care or helps you take care of your children?

[Do not read out; circle only one answer]

I take care of them myself	1
My spouse/partner	2
My parent	3
A family member (brother, sister, cousin, aunt, etc.)	4
A friend	5
Person with disability pays someone	6
Children are old enough and take care of themselves	7
Other (specify) _____	8

Craig Hospital Inventory of Environmental Factors

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation. First of all, do you think **you** have had the same opportunities as other people to participate in and take advantage of:

education ___ yes
employment ___ yes
recreation/leisure ___ yes

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never**. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

(Note: if a question asks specifically about school or work and you neither work nor attend school, check not applicable)

	Daily	Weekly	Monthly	Less than monthly	Never	Not applicable	Big problem	Small problem
1. In the past 12 months, how often has the availability of transportation been a problem for you? When this problem occurs, has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
2. In the past 12 months, how often has the design and layout of your home made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
3. In the past 12 months, how often has the design and layout of buildings and places you use at school or work made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o

4. In the past 12 months, how often has the design and layout of buildings and places you use in your community made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○
5. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○

	Daily	Weekly	Monthly	Less than monthly	Never	Not applicable	Big problem	Small problem
6. In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
7. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
8. In the past 12 months, how often has the availability of the education and training you needed been a problem for you? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
9. In the past 12 months, how often has the availability of health care services and medical care been a problem for you? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
10. In the past 12 months, how often has the lack of personal equipment or special adapted devices been a problem for you? Examples might include hearing aids, eyeglasses or wheelchairs. When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
11. In the past 12 months, how often has the lack of computer technology been a problem for you? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
12. In the past 12 months, how often did you need someone else's help in your home and could not get it easily? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o

13. In the past 12 months, how often did you need someone else's help at school or work and could not get it easily? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
14. In the past 12 months, how often did you need someone else's help in your community and could not get it easily? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
15. In the past 12 months, how often have other people's attitudes toward you been a problem at home? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
16. In the past 12 months, how often have other people's attitudes toward you been a problem at school or work? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
	Daily	Weekly	Monthly	Less than monthly	Never	Not applicable	Big problem	Small problem
17. In the past 12 months, how often have other people's attitudes been a problem in the community? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
18. In the past 12 months, how often has a lack of support and encouragement from others in your home been a problem? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
19. In the past 12 months, how often has a lack of support and encouragement from others at school or work been a problem? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o
20. In the past 12 months, how often has a lack of support and encouragement from others in your community been a problem? When this problem occurs has it been a big problem or a little problem?	o	o	o	o	o	o	o	o

21. In the past 12 months, how often did you experience prejudice or discrimination? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○
22. In the past 12 months, how often has the lack of programmes and services in the community been a problem? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○
23. In the past 12 months, how often did the policies and rules of businesses and organisations make problems for you? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○
24. In the past 12 months, how often did education and employment programmes and policies make it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○
25. In the past 12 months, how often did government programmes and policies make it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	○	○	○	○	○	○	○	○

EQ-5D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about	❑
I have some problems in walking about	❑
I am confined to bed	❑

Self-Care

I have no problems with self-care	❑
I have some problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑
I have some problems with performing my usual activities	❑
I am unable to perform my usual activities	❑

Pain/Discomfort

I have no pain or discomfort	❑
I have moderate pain or discomfort	❑
I have extreme pain or discomfort	❑

Anxiety/Depression

I am not anxious or depressed	❑
I am moderately anxious or depressed	❑
I am extremely anxious or depressed	❑

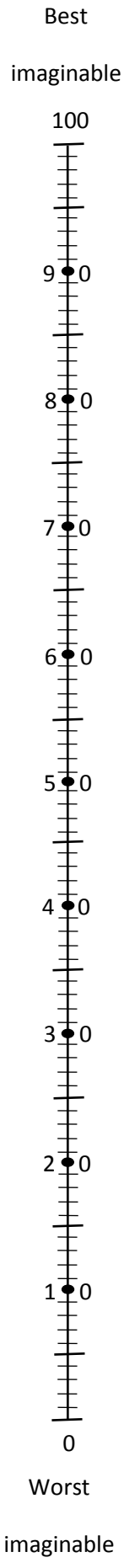
Compared with my general
level of health over the past 12 months,
my health state today is:

Better	❑	PLEASE TICK
Much the same	❑	ONE
Worse	❑	BOX

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state



World Health Organisation Disability Assessment Schedule II
Phase 2 Field Trials - Health Services Research

36-Item Self-Administered Version

H1	How do you rate your overall health in the past 30 days?	Very good	Good	Moderate	Bad	Very bad

This questionnaire asks about difficulties due to health conditions. Health conditions include disease or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the last 30 days, how much difficulty have you had in:						
	Understanding and communicating					
D1.1	Concentrating on doing something for ten minutes?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D1.2	Remembering to do important things?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D1.3	Analyzing and finding solutions to problems in day to day life?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D1.4	Learning a new task, for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D1.5	Generally understanding what people say?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D1.6	Starting and maintaining a conversation?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
	Getting around					
D2.1	Standing for long periods such as 30 minutes?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D2.2	Standing up from sitting down?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D2.3	Moving around inside your home?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D2.4	Getting out of your home?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D2.5	Walking a long distance such as a kilometre (or equivalent)?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
	Self Care					

D3.1	Washing your whole body?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D3.2	Getting dressed?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D3.3	Eating?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D3.4	Staying by yourself for a few days?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
	Getting along with people					
D4.1	Dealing with people you do not know?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D4.2	Maintaining a friendship?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D4.3	Getting along with people who are close to you?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D4.4	Making new friends?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D4.5	Sexual activities?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
	Life activities					
D5.1	Taking care of your household responsibilities?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D5.2	Doing most important household tasks well?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D5.3	Getting all the household work done that you needed to do?	None	Mild	Moderate	Severe	Extreme/ Cannot Do
D5.4	Getting your household work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme/ Cannot Do

IF YOU WORK (PAID, NON-PAID, SELF EMPLOYED) OR GO TO SCHOOL, COMPLETE QUESTIONS D5.5-D5.8 BELOW. OTHERWISE, SKIP TO D6.1 BELOW.

	In the last 30 days, how much difficulty did you have in:					
D5.5	Your day to day work/school?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D5.6	Doing your most important work/school tasks well?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D5.7	Getting all the work done that you need to do?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D5.8	Getting your work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme / Cannot Do

	In the last 30 days:					
	<u>Participation in society</u>					
D6.1	How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.2	How much of a problem did you have because of barriers or hindrances in the world around you?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.4	How much time did you spend on your health condition, or its consequences?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.5	How much has your health been a drain on the financial resources of you or your family?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.6	How much of a problem did your family have because of your health problems?	None	Mild	Moderate	Severe	Extreme / Cannot Do
D6.7	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	None	Mild	Moderate	Severe	Extreme / Cannot Do

H2	Overall, how much did these difficulties interfere with your life?	Not at all	Mildly	Moderately	Severely	Extremely
H3	Overall, in the past 30 days, how many days were these difficulties present?	RECORD NUMBER OF DAYS ___ / ___				
H4	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	RECORD NUMBER OF DAYS ___ / ___				
H5	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	RECORD NUMBER OF DAYS ___ / ___				

Thank you.

Self-described causes of disability

Nomsa can't do, without a walking stick. Course by high blood and artheritus Doctor at Jooster confirmed me as condemed
problems with legs caused by Polio, shoes are making life difficult
Confined to bed, stage 4 AIDS, uses Neighbours wheelchair to get around
She is unable to walk without a walking stick, having problems getting off her bed and going to the toilet.
I lost my eyesight through high blood pressure I experience cramp pains while I am on treatment. The doctors diagnosed sugar diabetes, I have moving problems.
Epileptic and crippled on left leg through car accident.
I very much loose balance from my knees which make me to use a walking stick. I spend most of my time in bed watching tv
Keneth can not do without the support of a walking stick. His legs swells from the knees, when that strikes he has to stay in bed
Nomampondo is limps. She was discharged using two walking sticks. She now use one she has a very weak eye problem. She can not even read her cell phone
He can't walk long distances and also cannot read newspapers and he can't write letters because he is shaking
Richard still uses two long walking sticks. He fell from a moving truck after losing consetraition mentally. Which he only gainened in hospital. He lost contiousness
Getrude has to use two silver walking sticks, she used to use a walking range but it got broken. She is build nig (sic). Suffers from high blood pressure.
I can't go to the places that I used to go to. I even resigned from work because of my disability. I used to get money from work but now I must wait for the pension grant
Mpatiswa uses one hand for doing every thing his wright hand wrist was condemed through a gun shot
I am totally blind. I suffer from high blood and am asthmatic. I experience short breath
I cam't even read my bible or see from a close distance. Doctors promised me an operation.
I Cant do anythin

Jessie uses a walking range after having a left hip operation twice, one in 192000 (*sic) second 2005. Through bone problems and extreme pains.
My feet get swollen not allowing me to move around when that happens I use walking crutches.
One wright (sic) working hand and one slightly crippled left leg
I cant do anything
I cant' walk around need assistance. I use a walking range
I can't do my usual activities, I can't walk by my self. If I want to go and see one of my family I must use a wheelcahir even there I must go with someone else
Difficulty in walking about. She trips and falls
I am unable to do my usual activities and i can't use public transport like others
As I can't walk I use a wheelchair I found myself in big difficulty when I want to go to the shop church etc. because I must ask someone in the house to push me. Sometimes the become cross or angry
I got a accident I was in the car driving to easten cape
I was in a car accident in 2004 November, then i lost my leg (right)
Because of my disability I lost my work that I was earning better money now I became a driver
I can't hear what people say but I'm using sign language
Degenerative lesion of the lumbar spine resulting in nerve entrapment. She suffers from back pains, limps when her pains strike its hard for her to move around
Difficulty in walking or running . Most of the problem would start from the knee and shoulder. He has a weak eyesight when reading
From my knee down I swell too much and have pains. High blood pressure, sirikes (sic) and I depend on medication
He is physically disabled on the left leg and arm, he cannot move without his walking stick, he mumbles when talking, speech problem!
He is using a wheelchair so he can't walk alone a long kilomiter because we are on the sharkes and the road is a gravel road
He limps on his right leg and has a very weak eyesight

I am unable to use public transport, people treat me differently from others, sometimes I want to go to the shop by myself and it becomes difficult
I balance on my furniture when I move around my house and my walking stick, I use most of my time in bed watching TV
I can?t work properly, I can't eat the things I used to eat anymore
I can't work or do my usual activities. I can't even visit my other family members, I'm stuck in this house. I can't pay taxes and rates for our home.
I don't get a sleep each and every night. Its a sleepless night. Is see the thing that people cannot see. I alway shout to unseen thing and talk alone
I have arthritus and have to use a walking stick. I also have high blood pressure, sugar diabetes and a big problem with eye-sight. Sometimes I feel useless because of swollen legs. I cannot wait any longer to leave this earth
I have epilepsy. It attacks me on may occasions during the week. My wife has to stay at home to take care of me. I can't work because of my illness
I have lost my job because of my disability. I can't use my hands because one was cut off after accident
I suffer from memory after i got very sick and hospitalised. I had TB and also sugar diabetic was shooting high. I think i am going to lose my job because i don't do all the things as i was requested to do
It's hard for him to read or walk long distances
Mama Nozizwe must use a walk stick when she has to walk some distance. She borrowed from a neighbour. She is crippled
Mama Ruth depends on her wheelchair or would rather be in bed
Mr Mandla can uses a bamboo walking stick he has very much of a problem using stairs
My legs are too stiff its hard for me to walk especially a long distance I just have to walk and stop until I get ready to take another step
Problem without her walking stick. I experience my legs locking, it makes it hard to lift my feet being very painful.
She cannot walk without the support of a walking stick.
She is Bedridden. She uses a wheel chair to move around. She also sufer from epilepsy

She uses a walking stick - Her feet swells and have painful knees. Through high blood and heari problem + Artheritus
She's on the wheelchair and laying on the bed in old for her to move. She must get somebody else to lift her up
Shetshaba is borne physically challenge he can not walk at all
The old man uses his wheelchair but he is mostly in bed his illness seem to disturb his mind
There is a pain in my legs when I stand for more than a few minutes
Cannot walk at all. Legs painful, walking with crutches. Due to be operated for the second time on the right leg. First operation was on left.
I have a small machine in my ear
Makes walking difficult
Its makes me feel liked times Im fine and other times sick and bad
Dit is eintlik net my wat 'n groot probleem is, want dit vererger net die werk wat ek doen
Get tired and dizzy. Pain in lower back. Arms get sore and swollen at wrists. Frequent headaches
After polio attack, can't walk without assistance of crutches; can't stand long time - mostly right leg affected; so have to depend on left leg
Legs got sores and sometimes pain in midriff; get so severe that I become stiff
Legs stiff and painful - joints as if it could be arthritis
Don't see far; sometimes get headaches
Quadruplegic, can't walk, using wheelchair. Have to get private transport to go to town - taxis 98 to take me
When told to do something, he forgets to do so teachers complain about aggression
The one ear cannot hear anything. My legs are sore and pains a lot
Miscommunication
I can't walk far distances. I have a fleece over my eyes which affects my sight
Can't use left arm, nerve is not working and right arm is also not good anymore. Borsbeen ook gebreek in ongeluk

Kan niks vir myself doen nie. Moet andere vra om vir my te help.
Ek konie my was en aantrek nie. Ek loop met 'n stok, kanie alleen wees nie. Ek kan niks vir myself doen nie
Had a stroke only use one hand. Polio in the other hand. Had some difficulty to wash herself and to put on some clothes. Can't work anymore
Baie kort asem. Wanneer dit so warm is swoes asem. Bere kla dokters het haar gese kan niks doen nie kan nie maklik rondbeweeg. Dit is rolstoel
Pain
Baie dae,dan is my voette,seer.En dam kan ek nie veri loop,en link op my bene staan nie.
Dus ongemaklik om 2-3 keer en soms meer na te dink oor wat ek mee besig is- baie vergeet agtig.Kan ook nie baie lank konsentreer nie kry ook gereeld hoofpyne
Congenital degeneration of my "maicillas"- disease. No spectacle can help my eyes. Can't see at all sometimes and get periodical headaches.
Pimples all over my feet and legs and they got swollen/very painful/have to go to doctor for injection and pain tablets; then get better for sometime. Can't wear shoes or socks because sore bursts.
Kan nie goed sien veral in die winter, linker oog het 40% siy en regter oog 80% - linker oog kan glad nie ver sien. As gevolg van rug probleem word oog aan getas. Kan nie in die aand sien.
As gevolg van een been wat korter as die ander een is kan ek nie goed beweeg en rug probleme en het dit veroorsaak dat ek moes ophou werk.
Ek kani hoor as mense met my praat nie.
Make walking very difficult
It's not that difficult but I just get too tired when I'm walking
Kan nie die gesin onderhou. Tong dik, hand nie gebruik; been sleep
Kan nie self was en aantrek nie. Verlam aan die een kant. Kan net een arm gebruik. Kan nie werk nie.
Wife wash and feed him
No difficulty
Kan nie lang afstande loop nie. Verduur baie pyn sommige kere. Gedeelte van been swel geweldig

Can't hear properly. Children are teasing him because he can only hear with one ear. Must sit in front of class because he can't hear what teacher said
Kam hie verloop,kani trappe klim nie.
Kan nie goed lees nie,kan glad nie in aand bestuuk nie
Kan nie goed sien en lees
Very painful sometimes to the extent that I am unable to work
Hand dyn baie in bewolkte weeg baie keee is dit ongema klik on angleg my rug te was.Die hand kan ook nie lekker vat nie
Ek kan nie reg en ver ente loep nie,en my linker arm en hand is verlam
Could not working anymore
Could not do want I wanted to do anymore
gebeure wat lank gelede pkas gevvind het is ek geneig om te vergeet. Net wanneer ek moet lees
I can't see and could not eat or drink what I felt like and it is also difficult to get used to injecting myself
I cannot work because my feet swell too much and because of my weight my body pains. I have difficulty dressing me and to pick up things. Sometimes it is very hard
Because of my disability, I cannot walk far. My muscles are partially injured as well as my nerves. I have no feeling in parts of my legs
Can’t say when the problem started
Dit lyk asof my bors toe trek, as ek hoes is ek kort asem en moet 'n wyle wag voordat ek kan opstaan
My bors raak baie benoud en bewegig is baie moeilik
Even he had a bill he can't see properly. He need help at work to do task
Gestrem kan nie loop, praat nie. Kommunikeer net gebate, geluide. By die gesemheid het stroke gehad. Nou is hy bedkeend
Raak baie frustreerd. Verstaan nie altyd. Wil alles het soos ay wil. Verstaan nie altyd wat rondom haar aangaan. Standiges as anders
When its night fall my sight gets weaker

Al wat ek kan onthou,is dat ek sowat meer. As in jaag V/D stoep de trappt die pyies geval het.So het die pyn ma gekon and viegaan.Ma het my nie veel gestuur dank die het da begin, of dug beker ma die ouderdon.weet nie regtig nie my kind.
Sometimes she can't stand on her feet then she's in bed the whole day.
Gaatjie in oor, baie jare gelede, linker oor heeltemaal doof. Sig swak met bril.
Kan nie meer ver stap nie. My sig is baie swak kan glad nie ver sieni. Ek val baie.
Makes legs stiff. Legs pain and it makes life very difficult
Baie dinge wat jy nie self kan doen. Trappe ongemaklik by sekere gebiede om te loop, kan nie lank sit met die been
Ek kan nie ver loop nie. Kan nie trappe klim nie
Tired soon. Can't do household tasks well
Artiritis in altwee bene.Kan nie onthou nie.Het geval A.G.V.Die bene wat nie goed kan vas trap nie.Het n Kop Hou weg van val en steke by die oog.
My rug pyn sommige dae so dat ek n die bed moet bly.Ek moet my vron via my om skoene vas te maak. Ek kan te vinnig opstaan as ek le of sit nie.
Party dae is my bors heelwat toe getrek dan kan ek niks doen nie.Ek moet dan order mense via om my werk te kom doen.
Ek kan mie my urou help nie want ek is Sele nie gesand nie.Ek wil haar so giaag help want sy sit in n rilstoel.
Can't talk or hear; has pains around throat and ears because of operation he underwent in 2005
Left eye totally blind; right eye farsighted
Can't put up things without the others hand. Can't put on alone his clothes. Can work with only one hand
As loop dan pyn bere. Kan nie wel loop. Kop is dronk, moeg
Have difficulty to walk distances. Get quickly tired. Can't do all the things. Must sit a while
I'm paralysed from my waist down (paraplegic) steps limit, transport
Ek voel by tye ek is 'n las vir my kinders
Ghost pain, that is a problem

Behalwe dat die helfte van my organe(baarmoede,lever,pangerias)al ingegee het is ek baie positief.
Kan nie meeg goed doen,waaraan hy gewoont was nie.Wil nog werk nie
Moet alles vra, want ek verstaan nie altyd
Moet die kinders altyd vra om my te help
Ek moet die kinders vra om my met alles te help. Dit laat my so hulpe loos voel.
Party keer moet ek vra vir hulp ma sukkel ma om.
Completely paralysed and can't see. When going long distances; uses wheelchair
Ek voel nou bietjie beter mar sodra dit warm raak, kry ek niks gedaan, soek moet vroeg op. Ek raak gedurig benoud, my oe kanie reg sien agv die swakheid, ek kanie ver loop nie
Ek kan nie te vinnig loop nie. Ek kan nie vinnig opstaan nie
I can't do my usual activiites by myself. I sometimes forget to do the most important things, maybe about a week. I can't walk, my legs are not strong. I am using a wheelchair. My left arm is paralysed
I don't work anymore.
It's hard for me to do my work at home because my two fingers on my left hand have been chopped out by the Doctors Because I have Diabetes and Heart Disease
Its not easy for me to lift up the things that are on top of something. E.g to put plastics on the table
Thozama also uses a walking stick
His chest becomes constricted and he comes short of breath
nee wat my toestand os ohder beheer
Elke doq ervaar ek pyn as gevolq van artritus. Die depressie is nie so qroot problem as ek net my medikasie qebrui.
Dit is as gerolg vin ouderdom wat kniee ingegee het
Because if diabetes his legs have been amputated
Hipbone was broken when he fell from his bed
Sometimes she only lay down because of the pain. She can't do as much of her day-to-day tasks. She can't walk long distances

Cant walk long distances
Skielik begin seerraak en geswel (geblaas).
Kan nie goed sien en in die aand glad nie lees of sien. Kan nie alleen stap, veral in die aand.
Baie lusteloos, baie pyn; kan nie ver loop. Het stroke gehad
Ek kan niks vir myself doen nie altwee my bene is afgesit.
Back pain when sitting up and down, walking and sitting for too long.
Ek kan party dae glad nie my dag takies doen nie en het baie pyn ek kan ok nie meer ver loop en moet versigtig wees as ek goed optel want dit val somer vit my hande vit
Cannot read or write anymore, cannot move around like before
Can't see very well and has asthma, Finds it difficult to walk because of back problem
Enilel snel. Kan nie trap op voet. Verdeur baie pyn/ Kan nie baie lank staan op bene, dan swel die enkel. Kani nie werk asgevolg van die enkel. Verduur baie pyn en swelsel
Always depressed. Times that can't cope to task in the house. Must drink pills to feel better every day.
Extreme pain
Baie dae kan ek nie lekke vat nie,want my arms pyn.My gedagtes is ook lekke nie,want ek veegeet sommiqe tye.waah ek sekere goed gesit het.*
He is taking it very hard because he was always hardworking person
Knie is van so aart dat ek dalk op ouderdom 55 knie vervanging moet kry ortopetiese verslag, medekasie net verligting. Loop moeilik met knie linker knie.
Kan nie meer goed sien nie. Niks onthou wat gebeur nie.
Raak kwaad en frustreerd omdat sy nie kan loop. Verduur die pyn in die bene. Kan net kort afstande loop
Kan nie ver loop. Kan nie met hande was nie. Partykeer baie pyn afhanklik van pille
Baie teneergedruk; kan nie ver loop; verskriklik moeg. Kan nie baie meer op bene staan. Baie pyn in bene
ek moet altyd mooi luister wat ander mense vir my se of vra

Soms is my bloed so hoog dat ek in die bed moet bly. Die arthritis laat my liggaam so pyn dat ek my niggie soms moet vra om my huis takies te doen.
Dink ni aan haan toestand,want dit maak siek,vat elke dag soos hy kon.Baie dae moeg
Ek kan nie so goed sien, kan nie dag take verrig en kani werk asgevolg van sig. Ek kani op my eie dorp toe gaan, kan nie ligte sien.
Kan glad nie meer werk nie en dokters kan niks meer doen nie.Ek kan ok nie meer rond beweeg soos ek altyd gedoen het nie.
After he was operated for meningitis a year later it resulted to epilepsy he ever just fall from standing for a long time even when walking. He says he does not drink alcohol or smoke
Chalton limps when walking. He is born with uneven legs
Eliot who is at a stage four HIV. Status gets challenge by opportunistic infection that partially cripples him. Suffers from cramping legs loses weight while on ARVs treatment. A very short tempered person
Epileptic. So much so that he uses medication every day
First of all I can say I experienced a lot of difficulties because as from that time I got this disability I lost my job and my future become to the dark place.
From the day I got this problem it became a problem because some of the things I used to do I can't do now by myself. I also lost school because of my disability
Gets mentally disturbed at times. Talks to himself in isolation. When he fights we have to tie his legs and hands. Take him to Valkenburg Hospital
He can't do anything other than sit in his own wheelchair. He was born disabled and can't walk
He hasn't experienced any difficulties yet
His leg was amputated above the knee after a taxi driver fight, he was one of the taxi drivers who got shot.
I can't do most things that I want by myself I must ask someone to do it and I am always stressed because I see that I am different to others that are normal. (Mentally disturbed completely-note written in different handwriting)
I can't do my usual activities.
I can't read and right. I dropped the school early because of my disability. Sometimes I feel rejected by my friends because of my disability

I experience a lot of challenges of painful bone because of Arthritus, sugar Diabetes etc and depression. So I can't stand being with company
I experienced a lot of difficulty because of my disability because now I can't work and I can't go to the places I used to go before
I get worse in winter I get much bone pains. I was twice involved in a car accident and I depend on my athritis medication, I don't walk normally as you can see I limp
I think she has a lot of problems like diabetes, high blood [pressure] arthritis, complete blindness and hearing problems. Disabled person adds: I have everything painful
I use a wheelchair to go around, I can't walk at all.
I'm unable to use public transport and i can't walk without my wheelchair. So i am unable to perform my usual activities
Monde is a polio patient from 2 years of age.
Mzikayise is partially crippled after he had meningitis illness from his discharge he had to use two long walking sticks and had to be put off from work. He even does not have the right speech.
Nozuko gets mentally disturbed. She breaks wall photos, televisions. She has to be locked up in the house when the family has to go somewhere.
She cannot do anything because of her disability.
She is mentally disturbed
She was born physically disabled. She limps when walking her arms are not straight.
Slow learner he had to be taken out of a normal school to a special school by a psychologist at Siwiwe School of Skills but he have now lost interest
Terrible Headache, weak eyesight, my whole body would feel weak
The difficulty that I experienced is that most of the time when I come back home I have to stay inside the house and my friends are not like they are normal so sometimes I feel small alhtough they love me so much
The doctor says he had meningitis that is why he is too slow to do things and also to think he is too slow
Xolani is bound to a wheelchair through his feet that have no feeling.
Xolela was born physically disabled but manages to walk using a walking stick. At the age of 25 he started being epileptic til now. He uses his medication from my support said the mother.

Leg was operated and becomes painful and I become short of breath when walking for too long
Ek kannie ver lank loop nie. Ek kannie buk nie. Ek kannie lekker trappe klim nie
Can't see completely or hear
Ek moet vra om my te bad en aan te trek
Cant do want I want to do
No difficulty
Kan nie ver afstande loop nie. Het baie pyn in bene. Kaan haar nie self was nie afwaslik van ander ona te was en asem te trek
Kan nie praat nie. Kan nie konsentreer nie. Kan niks vir haarself doen nie.
Baie mismoedig omdat sy nie kan loop nie. Baie pyn in bene en spasma
Sy amgewing woor by woon is nie rolspoel vreidelik nie.Dit is maeilil om hom van die een pleh na die ander te beweeg
Moet baie vra vir hulp. Ek word gespot en ongekyk.
Get tired quickly
Can't see far - sight blurring. AT night much more difficult. Started getting headaches after wearing spectacles from Phelophepa
Forget when I've put things or what day it is
My daughter got brain damage at birth
I can't go to the clinic by myself or do the things I used to do by myself because I'm in a wheelchair.
My son is mentally handicapped from birth. He is taking treatment for disability. He doesn't communicate with me very well. If I say something he thinks I've said something bad about him and gets angry
People always laugh at me when I try to speak because they do not understand what I am trying to say
I can't see with wearing glasses.And the glasses is sometimes a burden.It focus the peoples attention on my eyes
Meningitis - was diagnosed at 2 months. Completely retarded

My Familie moet met my buiten gewoon.Hard praat,as hulle saam my praat. Op skool was dit nogal n probleem.Dus hoekom ek nie skool voltooi het nie.
He cannot do anything, he's in a wheelchair
I can't do anything
She is confined to bed the person is fed by means of a pipe. She was at first treated for high blood pressure that led to a stroke. I get helped by home based carers.
She is mostly bed ridden.. Can't wash herself. She need to be assisted with everything. She struggles even when walking with her stick
She's disabled and confined in bed, she can move, she doesn't have legs because of diabetes the two legs have been cut out, she's using wheelchair if she wants to move around
Ek moet eers wag tot my dogter uit die werk, kom om my te was.Nie lekker om afhanklik te wees van andere.
Voet is baie dik geswel, kan nie goed loop. Kan nie aan aktiwiteite deelneem nie.
Kan nie meer uit gaan dorp toe of gaan werk nie kan ook nie lekke kuier saam vriende nie kan nie altyd hoor wat hul se
Asthmatic short breath through arthritis I have a painful arm from my legs I experience cramps
Bethwell suffers from stroke that totally affected his speech. He had to join speech therapy but late. He uses a walking stick to move.
Both legs get stiff from the back muscles and get swollen, I have to use my neighbour's walking stick even when I go to the pay point.
He has weak eyeside (sic eyesight?) when he reads his letters he needs help. He used to work as a brick layer but he now works as a part time cleaner depending on his disability grant. He also complains of painful back pains
He suffer from epilepsy that even took him out of work
I am unable to go to town alone I must depend on other person if he/she refuse then it means I won't go, because I am using a wheelchair
I can't go where I want to go alone because I am now blind, I can't even go to buy bread at the shop no matter how hungry I am, I must wait for someone to come and help me.
I can't use my left hand is locked.

I just experienced a few things because I was born like this I have learnt to do most things by my self as from when I was young.
It's not easy to go to the places that used to go before I might ask someone to go on my behalf sometimes people get tired because of me
Khunjulwa limps after she was burnt in a shack by a jealous boyfriend. She got saved by neighbour her right leg change shape. Use a walking stick
Mentally disturbed, he talks to himself, throws stones at passers-by. The illness stops sometimes and communicate with people. He gets a grant specially for this illness.
One leg has been amputated in 2009 due to diabetes. She also has a speech problem
People are always laughing when they see me. All in all they are discriminating me because of my disability
The difficulty I experienced in my life is that now I am working seated in my wheelchair, I can't run anymore as I used to do before.
The person is mentally disturbed which is getting worse, he mostly talks alone and you understand what he says (sic)
When striken by illness it courses him to be bedriden then he relise on a walking stick is criple
Walk with help of crutches; legs become weak when walking long distances
Can't work; left leg paralysed
Can't do anything for himself, can't work
Verstaan nie die mense nie. Kan nie konsentreer nie. Moet gehelp word om aan te trek en te bad.
Hy moet altyd ander toesig wees ons kan hom nie alleen los nie
Person had a stroke, since childhood abnormal, couldn't draw a line or use hands
Andile can not walk at all. He depends on a weelchair that needs repairs
I am HIV positive infect. I have AIDS. I have so many illnesses now, such hearing problem, sugar diabetic, high blood, rembering and concentration, severe headace. I'm sick all the time
I can't walk. I can't do my usual activities. I can't wash or dress myself. Actually I can't do anything myself
Madoda limps through injury of his spine. Winter he uses a walking stick he got stabed in a gang fight

Xolani suffers from epilepsy and had partially lost his speech.
Hy kan nie werk nie, was in 'n spesiale skool, het nie formele kwalifikasie. Kan nie alby arms gebruik.
She needs help all the time.
Eyes has been affected by diabutes and has to be helped when washing because can't walk properly
Not been able to walk without any help , I get angry when people don’t take care of their health, cause my problem was caused by lack of calcium.
Sometimes he get deppressed because he can't do things himself
Moet alles vir hom doen.
Lighting disturbing; head aches at front, late can't read, white residue on corners of eyes
Dit bienvloed my asemhaling en ek is gedurig angstig agv my bors
Moet ander mense vra om my met alles te help. Moet mense betaal om my kliniek toe te neem want ek het net 'n rolstoel nie.
Mense lag altyd as ek se ek kan nie lees of skryf nie
Net my een oog kan siendie een is blind.Kan nie in die aand dien nie .Kan nie ver sien met die een oog nie.
Sometimes she get angry because she can't do somethings on her own .She always just wants to be alone.
I'm sleeping on the bed, I cannot do anything by myself, even if I want to go to the toilet I have to get assistance from somebody else to lift me up.
Winie pulls he rleg when walking. She suffer from high blood and sugar diabetes. She has been mentally challenged and ended in Volkenburg and is still Epileptic
I am very in patient.I am always seeking for attention and love. Sometimes people are buzy
Amputation of right leg below knee
Becoming blind
Blind
Cannot do usual acitivities
Cannot walk Long distances

Cannot walk properly
Cant read
Depends on walking stick
depends on walking stick, Less respected
Difficulty working for children and uneducated
Does not have legs because of diabetes
Entire body gets weak and painful, dizzyness
Epileptic and ashma
Epileptic and ashma
He got shot in axile and being suffering from atheritus. He uses a walking stick. He limps when walking
He limps through gunshot injury. He gets mentally disturbed, collects rubbish from outside and brings into our yard. Isolates himself and talks to himself mumbling
He limps when walking, suffering from spinal pains, he cannot manage to work standing for more than ten minutes
heart problem,partially cripple, slow learner
I cant see properly
I sometimes have difficulty with remembering. I even don't have friends in my community because their parents say they will also become mental disabled if they come and play with me.
I'm struggling to walk. I walk slowly and I am unable to walk a long distance. I also sometimes lose my memory, not knowing who I am
In wheelchair, after gang fight
Limps
My son fell from the scaffle. This accident occurred when he fell down from the highest floor of the building to the ground. He was at the construction site, since now he is mentally handicap
Paralysed
People in community have wrong attitude on him, he won't stay alone even for one hour

problems balancing, use a walking stick
Right arm does not work, hard to walk and wash
She got epilepsy (fits)
She has a hearing problem, also mentally disturbed.
She limps and uses a long aluminium stick
She was born physically challenged. She is confined to a wheelchair
stiff legs, loss of memory
The old man must use crutches to move around. Suffer from prostate cancer arthritis seeing, even when wearing glasses through high blood.
Unable to bend down, dress self, body numb when walking, weight gain
Walking range to move around
Walking stick
Gate in my oodromme. Ek het in albei oordromme buisies om te verhoed dat die oordrom me bars. Ek is al deur 2 operasies
Dir artritus is n problem want die pyn is soos lets wat vreet binne jou liggoam. My vergeetagtigheid is me so groot problem me
As gevolg van my bloeddruk is my oe oangetas en dit is in problem wat gereeld voorkom
van kinderdae af, kan vie goed onthouven lionsentrar, verstandelik gestrem-kin vie werk
Kan glad nie werk asgevalg van my rug probleem en my oe
Spiere is angetas, fibromyosites-sielite kun vie goed loop en beweeg nie
Kan nie meer werk of ver loop kort van asem heel tyd moeg en sukkel om te slaap
Kan nie loop nie. Sit in rolstoel. Kan nie homself was en aantrek nie. Het nie pyn
Ek is gestiant tot die huis kan nie it beweeg
Ek is gestrant tot die huis , kan nie it beweeg
Tien jaar gelede a stroke gehad en dit het veroorsaak dat linkerkat verlam is, het geval en linkerbeen se knie seergemaak kan ver goed loop nie

een oor heeltemal doof-kan vie goed hoor spraak aangetas na stroke-praat moeilik
Dis moeilik vir my om rond te jag en alles te doen en wat dit nog moeiliker maak is dat ek maar van 2009 nie meer gebruik het van my bene nie
Hy is maklik aandaq afleibaar en dit effekteer sy studies. Hy is baie ongemaklik met kontaklense asook brill, maar daarsonder is sy sig vir hom n probleem
Can't eat certain food anymore, the tablets I used to drink affected my liver, my sight is also not good because of that
hy kan vir homself nie versorg nie

Raw WHOQOL-BREF data

			Oudtshoorn	N=175	Nyanga N=141		Total	N=316
Domain	Question		Count	Column N %	Count	Column N %		
	How would you rate your quality of life?	**Very poor**	**9**	**5.10%**	**16**	**11.40%**	**25**	**7.90%**
		Poor	**26**	**14.90%**	**46**	**32.90%**	**72**	**22.90%**
		Neither poor not good	58	33.10%	46	32.90%	104	33.00%
		Good	73	41.70%	30	21.40%	103	32.70%
		Very good	9	5.10%	2	1.40%	11	3.50%
	How satisfied are you with your health?	**Very dissatisfied**	Not asked		**28**	**20.00%**	**28**	**20.00%**
		Dissatisfied			**47**	**33.60%**	**47**	**33.60%**
		Neither satisfied nor dissatisfied			42	30.00%	42	30.00%
		Satisfied			21	15.00%	21	15.00%
		Very satisfied			2	1.40%	2	1.40%
Physical	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	**Not at all**	12	6.90%	20	14.30%	32	10.20%
Physical	Do you have enough energy for everyday life?	An extreme amount	**17**	**9.80%**	**1**	**0.70%**	**18**	**5.80%**
		Not at all	**7**	**4.20%**	**12**	**8.60%**	**19**	**6.20%**
		A little	**4**	**2.40%**	**31**	**22.10%**	**35**	**11.40%**
		A moderate amount	47	28.00%	51	36.40%	98	31.80%
		Very much	96	57.10%	41	29.30%	137	44.50%
		An extreme amount	14	8.30%	5	3.60%	19	6.20%

Physical	How well are you able to get around?	**Very poor**	**34**	**19.70%**	**27**	**19.60%**	**61**	**19.60%**
		Poor	**41**	**23.70%**	**41**	**29.70%**	**82**	**26.40%**
		Neither poor not good	41	23.70%	40	29.00%	81	26.00%
		Good	37	21.40%	29	21.00%	66	21.20%
Physical	How satisfied are you with your sleep?	**A little**	37	21.30%	39	27.90%	76	24.20%
		Very good	20	11.60%	1	0.70%	21	6.80%
		Very dissatisfied	**23**	**13.30%**	**9**	**6.40%**	**32**	**10.20%**
		Dissatisfied	**31**	**17.90%**	**21**	**15.00%**	**52**	**16.60%**
		Neither satisfied nor dissatisfied	50	28.90%	58	41.40%	108	34.50%
Physical	How satisfied are you with your ability to perform your daily living activities?	Satisfied	51	29.50%	48	34.30%	99	31.60%
		Very satisfied	18	10.40%	4	2.90%	22	7.00%
		Very dissatisfied	**14**	**8.00%**	**19**	**13.70%**	**33**	**10.50%**
		Dissatisfied	**33**	**19.00%**	**46**	**33.10%**	**79**	**25.20%**
		Neither satisfied nor dissatisfied	23	13.20%	56	40.30%	79	25.20%
Physical	How satisfied are you with your capacity for work?	Satisfied	86	49.40%	17	12.20%	103	32.90%
		A moderate amount	43	24.70%	41	29.30%	84	26.80%
		Very satisfied	18	10.30%	1	0.70%	19	6.10%
		Very dissatisfied	**25**	**14.50%**	**38**	**27.10%**	**63**	**20.10%**
		Dissatisfied	**39**	**22.50%**	**37**	**26.40%**	**76**	**24.30%**
		Neither satisfied nor dissatisfied	39	22.50%	47	33.60%	86	27.50%
		Satisfied	63	36.40%	15	10.70%	78	24.90%

		Very satisfied	7	4.00%	3	2.10%	10	3.20%
		Very much	**76**	**43.70%**	**33**	**23.60%**	**109**	**34.70%**
		An extreme amount	**6**	**3.40%**	**7**	**5.00%**	**13**	**4.10%**
Physical	How much do you need any medical treatment to function in your daily life?	**Not at all**	36	20.70%	23	16.70%	59	18.90%
		A little	33	19.00%	59	42.80%	92	29.50%
		A moderate amount	38	21.80%	37	26.80%	75	24.00%
		Very much	**50**	**28.70%**	**18**	**13.00%**	**68**	**21.80%**
Psychological	How much do you enjoy life?	**Not at all**	**20**	**11.40%**	**18**	**13.20%**	**38**	**12.20%**
		An extreme amount	21	12.20%	4	2.90%	25	8.00%
Psychological	How well are you able to concentrate?	**Not at all**	**7**	**4.00%**	**9**	**6.50%**	**16**	**5.10%**
		A little	**9**	**5.20%**	**23**	**16.50%**	**32**	**10.30%**
		A moderate amount	32	18.50%	62	44.60%	94	30.10%
		Very much	98	56.60%	35	25.20%	133	42.60%
		An extreme amount	27	15.60%	10	7.20%	37	11.90%
Psychological	Are you able to accept your bodily appearance?	**Not at all**	**11**	**6.40%**	**17**	**12.20%**	**28**	**9.00%**
		A little	**27**	**15.60%**	**18**	**12.90%**	**45**	**14.40%**
		A moderate amount	55	31.80%	53	38.10%	108	34.60%
		Very much	61	35.30%	44	31.70%	105	33.70%
		A little	**25**	**14.30%**	**23**	**16.90%**	**48**	**15.40%**
		An extreme amount	19	11.00%	7	5.00%	26	8.30%
Psychological	How satisfied are you with yourself?	**Very dissatisfied**	**31**	**18.00%**	**23**	**16.40%**	**54**	**17.30%**

Psychological	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Never	21	12.10%	11	7.90%	**32**	**10.30%**
		Dissatisfied	**49**	**28.50%**	**37**	**26.40%**	**86**	**27.60%**
		Seldom	21	12.10%	14	10.10%	**35**	**11.20%**
		Neither satisfied nor dissatisfied	33	19.20%	55	39.30%	88	28.20%
		Quite often	38	22.00%	42	30.20%	80	25.60%
		Satisfied	53	30.80%	22	15.70%	75	24.00%
		Very often	**71**	**41.00%**	**60**	**43.20%**	131	42.00%
		Very satisfied	6	3.50%	3	2.10%	9	2.90%
		Always	**22**	**12.70%**	**12**	**8.60%**	34	10.90%
		A moderate amount	46	26.30%	61	44.90%	107	34.40%
		Very much	61	34.90%	24	17.60%	85	27.30%
		An extreme amount	23	13.10%	10	7.40%	33	10.60%
Psychological	To what extent do your feel your life to be meaningful?	**Not at all**	**8**	**4.70%**	**10**	**7.20%**	**18**	**5.80%**
		A little	**11**	**6.40%**	**10**	**7.20%**	**21**	**6.80%**
		A moderate amount	54	31.40%	42	30.20%	96	30.90%
		Very much	78	45.30%	73	52.50%	151	48.60%
Social	How satisfied are you with your personal relationships?	**Very dissatisfied**	**16**	**9.20%**	**15**	**11.90%**	**31**	**10.40%**
		Very satisfied	31	17.80%	14	14.60%	45	16.70%
Social	How satisfied are you with the support you get from your friends?	Very dissatisfied	**17**	**12.90%**	**7**	**5.10%**	**24**	**8.90%**

		Dissatisfied	**14**	**10.60%**	**7**	**5.10%**	**21**	**7.80%**
		Neither satisfied nor dissatisfied	23	17.40%	58	42.00%	81	30.00%
		Satisfied	57	43.20%	60	43.50%	117	43.30%
		Very satisfied	21	15.90%	6	4.30%	27	10.00%
		Very dissatisfied	5	2.90%	6	4.30%	11	3.50%
		Dissatisfied	**33**	**19.10%**	**17**	**13.50%**	**50**	**16.70%**
		Neither satisfied nor dissatisfied	40	23.10%	38	30.20%	78	26.10%
		Satisfied	76	43.90%	51	40.50%	127	42.50%
Social	How satisfied are you with your sex life?	Very satisfied	8	4.60%	5	4.00%	13	4.30%
		Very dissatisfied	**5**	**2.90%**	**19**	**19.80%**	**24**	**8.90%**
		Dissatisfied	**17**	**9.80%**	**11**	**11.50%**	**28**	**10.40%**
		Neither satisfied nor dissatisfied	20	11.50%	26	27.10%	46	17.00%
		Satisfied	101	58.00%	26	27.10%	127	47.00%
Environmental	How safe do you feel in your daily life?	**Not at all**	**18**	**10.30%**	**15**	**10.80%**	**33**	**10.50%**
		An extreme amount	27	15.40%	5	3.60%	32	10.20%
Environmental	Have you enough money to meet your needs?	**Not at all**	**10**	**5.80%**	**92**	**66.20%**	**102**	**32.70%**
		A little	**21**	**12.10%**	**22**	**15.80%**	**43**	**13.80%**
		A moderate amount	38	22.00%	18	12.90%	56	17.90%
Environmental	How available to you is the information that you need in your day-to-day life?	Very much	70	40.50%	7	5.00%	77	24.70%
		An extreme amount	34	19.70%	0	0.00%	34	10.90%
		Not at all	**83**	**48.00%**	**17**	**12.10%**	**100**	**31.90%**
		A little	**23**	**13.30%**	**45**	**32.10%**	**68**	**21.70%**

		A moderate amount	32	18.50%	61	43.60%	93	29.70%
Environmental	To what extent do you have the opportunity for leisure activities?	Very much	24	13.90%	15	10.70%	39	12.50%
		A little	**22**	**12.60%**	**27**	**19.40%**	**49**	**15.70%**
		An extreme amount	11	6.40%	2	1.40%	13	4.20%
		Not at all	**15**	**8.70%**	**31**	**22.10%**	**46**	**14.70%**
		A little	**23**	**13.40%**	**42**	**30.00%**	**65**	**20.80%**
Environmental	How satisfied are you with the condition of your living place?	A moderate amount	49	28.50%	49	35.00%	98	31.40%
		Very much	60	34.90%	18	12.90%	78	25.00%
		An extreme amount	25	14.50%	0	0.00%	25	8.00%
		Dissatisfied	**9**	**5.20%**	**32**	**23.20%**	**41**	**13.20%**
		Neither satisfied nor dissatisfied	**20**	**11.60%**	**49**	**35.50%**	**69**	**22.30%**
Environmental	How satisfied are you with your access to health services	Satisfied	98	57.00%	43	31.20%	141	45.50%
		Very satisfied	40	23.30%	8	5.80%	48	15.50%
		A moderate amount	42	24.10%	54	38.80%	96	30.70%
		Very dissatisfied	**2**	**1.20%**	**6**	**4.30%**	**8**	**2.60%**
		Dissatisfied	**10**	**5.80%**	**26**	**18.70%**	**36**	**11.50%**
		Neither satisfied nor dissatisfied	22	12.70%	55	39.60%	77	24.70%
		Satisfied	108	62.40%	48	34.50%	156	50.00%
		Very satisfied	31	17.90%	4	2.90%	35	11.20%

Environmental	How satisfied are you with your access to transport?	**Very dissatisfied**	**4**	**2.30%**	**15**	**10.70%**	**19**	**6.10%**
		Dissatisfied	**18**	**10.50%**	**48**	**34.30%**	**66**	**21.20%**
		Neither satisfied nor dissatisfied	30	17.40%	47	33.60%	77	24.70%
		Satisfied	91	52.90%	26	18.60%	117	37.50%
		Very satisfied	29	16.90%	4	2.90%	33	10.60%
		Very much	67	38.50%	40	28.80%	107	34.20%
		An extreme amount	25	14.40%	3	2.20%	28	8.90%
Environmental	How healthy is your physical environment?	**Not at all**	**11**	**6.30%**	**15**	**10.70%**	**26**	**8.30%**
		A little	**9**	**5.10%**	**16**	**11.40%**	**25**	**7.90%**
		A moderate amount	32	18.30%	56	40.00%	88	27.90%
		Very much	96	54.90%	48	34.30%	144	45.70%

			Oudtshoor N=175		Nyanga N=141		Total	N=316
Domain	Question		Count	Column N %	Count	Column N %		
	How would you rate your quality of life?	**Very poor**	**9**	**5.1%**	**16**	**11.4%**	**25**	**7.9%**
		Poor	**26**	**14.9%**	**46**	**32.9%**	**72**	**22.9%**
		Neither poor not good	58	33.1%	46	32.9%	104	33.0%
		Good	73	41.7%	30	21.4%	103	32.7%
		Very good	9	5.1%	2	1.4%	11	3.5%
	How satisfied are you with your health?	**Very dissatisfied**	Not asked		**28**	**20.0%**	**28**	**20.0%**
		Dissatisfied			**47**	**33.6%**	**47**	**33.6%**
		Neither satisfied nor dissatisfied			42	30.0%	42	30.0%
		Satisfied			21	15.0%	21	15.0%
		Very satisfied			2	1.4%	2	1.4%

Physical	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	**Not at all**	12	6.9%	20	14.3%	32	10.2%
		A little	37	21.3%	39	27.9%	76	24.2%
		A moderate amount	43	24.7%	41	29.3%	84	26.8%
		Very much	**76**	**43.7%**	**33**	**23.6%**	**109**	**34.7 %**
		An extreme amount	**6**	**3.4%**	**7**	**5.0%**	**13**	**4.1%**
Physical	How much do you need any medical treatment to function in your daily life?	**Not at all**	36	20.7%	23	16.7%	59	18.9%
		A little	33	19.0%	59	42.8%	92	29.5%
		A moderate amount	38	21.8%	37	26.8%	75	24.0%
		Very much	**50**	**28.7%**	**18**	**13.0%**	**68**	**21.8 %**

		An extreme amount	**17**	**9.8%**	**1**	**.7%**	**18**	**5.8%**
Psychological	How much do you enjoy life?	**Not at all**	**20**	**11.4%**	**18**	**13.2%**	**38**	**12.2 %**
		A little	**25**	**14.3%**	**23**	**16.9%**	**48**	**15.4 %**
		A moderate amount	46	26.3%	61	44.9%	107	34.4%
		Very much	61	34.9%	24	17.6%	85	27.3%
		An extreme amount	23	13.1%	10	7.4%	33	10.6%
Psychological	To what extent do your feel your life to be meaningful?	**Not at all**	**8**	**4.7%**	**10**	**7.2%**	**18**	**5.8%**
		A little	**11**	**6.4%**	**10**	**7.2%**	**21**	**6.8%**
		A moderate amount	54	31.4%	42	30.2%	96	30.9%
		Very much	78	45.3%	73	52.5%	151	48.6%
		An extreme amount	21	12.2%	4	2.9%	25	8.0%
Psychological	How well are you able to concentrate?	**Not at all**	**7**	**4.0%**	**9**	**6.5%**	**16**	**5.1%**

		A little	**9**	**5.2%**	**23**	**16.5%**	**32**	**10.3 %**
		A moderate amount	32	18.5%	62	44.6%	94	30.1%
		Very much	98	56.6%	35	25.2%	133	42.6%
		An extreme amount	27	15.6%	10	7.2%	37	11.9%
Environmental	How safe do you feel in your daily life?	**Not at all**	**18**	**10.3%**	**15**	**10.8%**	**33**	**10.5 %**
		A little	**22**	**12.6%**	**27**	**19.4%**	**49**	**15.7 %**
		A moderate amount	42	24.1%	54	38.8%	96	30.7%
		Very much	67	38.5%	40	28.8%	107	34.2%
		An extreme amount	25	14.4%	3	2.2%	28	8.9%
Environmental	How healthy is your physical environment?	**Not at all**	**11**	**6.3%**	**15**	**10.7%**	**26**	**8.3%**
		A little	**9**	**5.1%**	**16**	**11.4%**	**25**	**7.9%**
		A moderate amount	32	18.3%	56	40.0%	88	27.9%
		Very much	96	54.9%	48	34.3%	144	45.7%

		An extreme amount	27	15.4%	5	3.6%	32	10.2%
Physical	Do you have enough energy for everyday life?	**Not at all**	**7**	**4.2%**	**12**	**8.6%**	**19**	**6.2%**
		A little	**4**	**2.4%**	**31**	**22.1%**	**35**	**11.4 %**
		A moderate amount	47	28.0%	51	36.4%	98	31.8%
		Very much	96	57.1%	41	29.3%	137	44.5%
		An extreme amount	14	8.3%	5	3.6%	19	6.2%
Psychological	Are you able to accept your bodily appearance?	**Not at all**	**11**	**6.4%**	**17**	**12.2%**	**28**	**9.0%**
		A little	**27**	**15.6%**	**18**	**12.9%**	**45**	**14.4 %**
		A moderate amount	55	31.8%	53	38.1%	108	34.6%
		Very much	61	35.3%	44	31.7%	105	33.7%
		An extreme amount	19	11.0%	7	5.0%	26	8.3%

Environmental	Have you enough money to meet your needs?	**Not at all**	**10**	**5.8%**	**92**	**66.2%**	**102**	**32.7%**
		A little	**21**	**12.1%**	**22**	**15.8%**	**43**	**13.8%**
		A moderate amount	38	22.0%	18	12.9%	56	17.9%
		Very much	70	40.5%	7	5.0%	77	24.7%
		An extreme amount	34	19.7%	0	0.0%	34	10.9%
Environmental	How available to you is the information that you need in your day-to-day life?	**Not at all**	**83**	**48.0%**	**17**	**12.1%**	**100**	**31.9%**
		A little	**23**	**13.3%**	**45**	**32.1%**	**68**	**21.7%**
		A moderate amount	32	18.5%	61	43.6%	93	29.7%
		Very much	24	13.9%	15	10.7%	39	12.5%
		An extreme amount	11	6.4%	2	1.4%	13	4.2%

Environmental	To what extent do you have the opportunity for leisure activities?	**Not at all**	**15**	**8.7%**	**31**	**22.1%**	**46**	**14.7%**
		A little	**23**	**13.4%**	**42**	**30.0%**	**65**	**20.8%**
		A moderate amount	49	28.5%	49	35.0%	98	31.4%
		Very much	60	34.9%	18	12.9%	78	25.0%
		An extreme amount	25	14.5%	0	0.0%	25	8.0%
Physical	How well are you able to get around?	**Very poor**	**34**	**19.7%**	**27**	**19.6%**	**61**	**19.6%**
		Poor	**41**	**23.7%**	**41**	**29.7%**	**82**	**26.4%**
		Neither poor not good	41	23.7%	40	29.0%	81	26.0%
		Good	37	21.4%	29	21.0%	66	21.2%
		Very good	20	11.6%	1	.7%	21	6.8%
Physical	How satisfied are you with your sleep?	**Very dissatisfied**	**23**	**13.3%**	**9**	**6.4%**	**32**	**10.2%**

		Dissatisfied	**31**	**17.9%**	**21**	**15.0%**	**52**	**16.6 %**
		Neither satisfied nor dissatisfied	50	28.9%	58	41.4%	108	34.5%
		Satisfied	51	29.5%	48	34.3%	99	31.6%
		Very satisfied	18	10.4%	4	2.9%	22	7.0%
Physical	How satisfied are you with your ability to perform your daily living activities?	**Very dissatisfied**	**14**	**8.0%**	**19**	**13.7%**	**33**	**10.5 %**
		Dissatisfied	**33**	**19.0%**	**46**	**33.1%**	**79**	**25.2 %**
		Neither satisfied nor dissatisfied	23	13.2%	56	40.3%	79	25.2%
		Satisfied	86	49.4%	17	12.2%	103	32.9%
		Very satisfied	18	10.3%	1	.7%	19	6.1%
Physical	How satisfied are you with your capacity for work?	**Very dissatisfied**	**25**	**14.5%**	**38**	**27.1%**	**63**	**20.1 %**
		Dissatisfied	**39**	**22.5%**	**37**	**26.4%**	**76**	**24.3 %**

		Neither satisfied nor dissatisfied	39	22.5%	47	33.6%	86	27.5%
		Satisfied	63	36.4%	15	10.7%	78	24.9%
		Very satisfied	7	4.0%	3	2.1%	10	3.2%
Psychological	How satisfied are you with yourself?	**Very dissatisfied**	**31**	**18.0%**	**23**	**16.4%**	**54**	**17.3 %**
		Dissatisfied	**49**	**28.5%**	**37**	**26.4%**	**86**	**27.6 %**
		Neither satisfied nor dissatisfied	33	19.2%	55	39.3%	88	28.2%
		Satisfied	53	30.8%	22	15.7%	75	24.0%
		Very satisfied	6	3.5%	3	2.1%	9	2.9%
Social	How satisfied are you with your personal relationships ?	**Very dissatisfied**	**16**	**9.2%**	**15**	**11.9%**	**31**	**10.4 %**
		Dissatisfied	**33**	**19.1%**	**17**	**13.5%**	**50**	**16.7 %**
		Neither satisfied nor dissatisfied	40	23.1%	38	30.2%	78	26.1%
		Satisfied	76	43.9%	51	40.5%	127	42.5%
		Very satisfied	8	4.6%	5	4.0%	13	4.3%

Social	How satisfied are you with your sex life?	**Very dissatisfied**	**5**	**2.9%**	**19**	**19.8%**	**24**	**8.9%**
		Dissatisfied	**17**	**9.8%**	**11**	**11.5%**	**28**	**10.4 %**
		Neither satisfied nor dissatisfied	20	11.5%	26	27.1%	46	17.0%
		Satisfied	101	58.0%	26	27.1%	127	47.0%
		Very satisfied	31	17.8%	14	14.6%	45	16.7%
Social	How satisfied are you with the support you get from your friends?	Very dissatisfied	**17**	**12.9%**	**7**	**5.1%**	**24**	**8.9%**
		Dissatisfied	**14**	**10.6%**	**7**	**5.1%**	**21**	**7.8%**
		Neither satisfied nor dissatisfied	23	17.4%	58	42.0%	81	30.0%
		Satisfied	57	43.2%	60	43.5%	117	43.3%
		Very satisfied	21	15.9%	6	4.3%	27	10.0%
		Very dissatisfied	5	2.9%	6	4.3%	11	3.5%

Environmental	How satisfied are you with the condition of your living place?	Dissatisfied	**9**	**5.2%**	**32**	**23.2%**	**41**	**13.2%**
		Neither satisfied nor dissatisfied	**20**	**11.6%**	**49**	**35.5%**	**69**	**22.3%**
		Satisfied	98	57.0%	43	31.2%	141	45.5%
		Very satisfied	40	23.3%	8	5.8%	48	15.5%
Environmental	How satisified are you with your access to health services	**Very dissatisfied**	**2**	**1.2%**	**6**	**4.3%**	**8**	**2.6%**
		Dissatisfied	**10**	**5.8%**	**26**	**18.7%**	**36**	**11.5%**
		Neither satisfied nor dissatisfied	22	12.7%	55	39.6%	77	24.7%
		Satisfied	108	62.4%	48	34.5%	156	50.0%
		Very satisfied	31	17.9%	4	2.9%	35	11.2%
Environmental	How satisfied are you with your access to transport?	**Very dissatisfied**	**4**	**2.3%**	**15**	**10.7%**	**19**	**6.1%**

		Dissatisfied	**18**	**10.5%**	**48**	**34.3%**	**66**	**21.2 %**
		Neither satisfied nor dissatisfied	30	17.4%	47	33.6%	77	24.7%
		Satisfied	91	52.9%	26	18.6%	117	37.5%
		Very satisfied	29	16.9%	4	2.9%	33	10.6%
Psychological	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Never	21	12.1%	11	7.9%	**32**	**10.3 %**
		Seldom	21	12.1%	14	10.1%	**35**	**11.2 %**
		Quite often	38	22.0%	42	30.2%	80	25.6%
		Very often	**71**	**41.0%**	**60**	**43.2%**	131	42.0%
		Always	**22**	**12.7%**	**12**	**8.6%**	34	10.9%

Algorithm for scoring the WHOQOL-BREF

SPSS syntax for carrying out data checking, cleaning and computing total scores

Check all 26 items from assessment have a range of 1-5

RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16

Q17 Q81 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26

(1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).

(This recodes all data outside the range 1-5 to system missing.)

Reverse 3 negatively phrased items RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1).

(This transforms negatively framed questions to positively framed questions.)

Compute domain scores COMPUTE PHYS=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4.

COMPUTE PSYCH=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4.

COMPUTE SOCIAL=MEAN.2(Q20,Q21,Q22)*4.

COMPUTE ENVIR=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4.

(These equations calculate the domain scores. All scores are multiplied by 4 so as

to be directly comparable with scores derived from the WHOQOL-100. The '.6'

in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated.)

Transform scores to a 0-100 scale COMPUTE PHYS=(PHYS-4)*(100/16).

COMPUTE PSYCH=(PSYCH-4)*(100/16).

COMPUTE SOCIAL=(SOCIAL-4)*(100/16).

COMPUTE ENVIR=(ENVIR-4)*(100/16).

Delete cases with >20% missing data COUNT TOTAL=Q1 TO Q26 (1 THRU 5).

(This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-BREF items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment.)

SELECT IF (TOTAL>=21).

EXECUTE.

(This second command selects only those cases where ‘total’, the total number of items completed, is greater than or equal to 80%. It deletes the remaining cases from the dataset.)

21.1 Recoding and Algorithm of the WHODAS 2.0

1_1

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D11.

RECODE

D1_2

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D12.

RECODE

D1_3

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D13.

RECODE

D1_4

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D14.

RECODE

D1_5

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D15.

RECODE

D1_6

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D16.

RECODE

D2_1

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D21.

RECODE

D2_2

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D22.

RECODE

D2_3

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D23.

RECODE

D2_4

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D24.

RECODE

D2_5

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D25.

RECODE

D3_1

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D31.

RECODE

D3_2

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D32.

RECODE

D3_3

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D33.

RECODE

D3_4

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D34.

RECODE

D4_1

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D41.

RECODE

D4_2

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D42.

RECODE

D4_3

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D43.

RECODE

D4_4

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D44.

RECODE

D4_5

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D45.

RECODE

D5_1

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D51.

RECODE

D5_2

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D52.

RECODE

D5_3

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D53.

RECODE

D5_4

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D54.

RECODE

D5_5

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D55.

RECODE

D6_1

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D61.

RECODE

D6_2

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D62.

RECODE

D6_3

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D63.

RECODE

D6_4

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D64.

RECODE

D6_5

(1=0) (2=1) (3=2) (4=3) (5=4) INTO D65.

RECODE

D6_6

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D66.

RECODE

D6_7

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D67.

RECODE

D6_8

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D68.

RECODE

D5_8

(1=0) (2=1) (3=1) (4=2) (5=2) INTO D58.

```
COMPUTE Do1=(D11+D12+D13+D14+D15+D16)*100/20.

COMPUTE Do2=(D21+D22+D23+D24+D25)*100/16.

COMPUTE Do3=(D31+D32+D33+D34)*100/10.

COMPUTE Do4=(D41+D42+D43+D44+D45)*100/12.

COMPUTE Do51=(D51+D52+D53+D54)*100/10.

COMPUTE DO6=(D61+D62+D63+D64+D66+D67+D68)*100/20.
```

Higher Certificate in Disability Practice Brochure with course outcomes

The Disability Studies Programme in the Department of Health and Rehabilitation Sciences was initiated in 2003 as the first of its kind on the African continent. This programme's vision is to forge disability inclusion in Africa. We aim to do this by taking an asset based approach to generating abilities and knowledge on disability inclusion with a specific focus on youth in Africa within a global context. This programme seeks to develop research and academic capacity that will contribute to the understanding of disability in context, as an issue of diversity and social justice.

To this end we offer a Higher Certificate in Disability Practice. This course may activate your interest in the other courses we offer ranging from short courses, postgraduate diploma, as well as research programmes at Masters and doctoral level.

The Higher Certificate in Disability Practice (NQF level 5) – 1 year

The Higher Certificate has been set up in collaboration with the Western Cape Department of Health and Rehabilitation Services to equip community health workers with the necessary skills and knowledge in working with children and adults with disabilities in their local communities. The course also provides prospective students with a pathway in which to study further in disability studies.

What will you learn?

The exit level outcomes of the certificate are for you to be able to:

1. Screen and identify disabled persons for impairments and functional ability and participation restrictions in the life areas of living, learning, working and socialising.

2. Apply essential methods, procedures and techniques to address impairments and functional limitations experienced by disabled persons and provide basic interventions to improve participation in the life areas of living, learning, working and socialising.

3. Implement health promoting actions, education and strategies.

4. Promote the rights of people with disabilities

5. Facilitate re-integration of disabled persons into home and community life

The certificate consists of 5 courses

Inclusive development and Agency – Promotes the rights of people with disabilities and examines implementation strategies to enable participation. Participants learn how to utilise the theories and skills using the CBR framework as a community strategy for disability inclusion.

Promoting healthy lifestyles – Explores how to implement health promotion actions, education and strategies. Participants learn how to utilise the theories and skills of asset building to enhance inclusion.

Disability information management and communication systems – Describe basic information systems and implement communication systems in relation to care pathways of people with disabilities.

Health Wellness and Functional Ability – Select and screen disabled clients for impairments and provide basic interventions to improve participation of in the life areas of living, learning, working and socialising.

Work integrated practice learning - Practice the ability to screen, provide basic care, follow-up and referral systems, as it relates to the needs of people with disabilities.

Who can participate?

To participate in this certificate the following requirements are needed:

- Matric certificate or National Senior Certificate for Adults (NASCA, NQF Level 4)
- Admission based on mature age of 22 years and over will be considered upon the completion of a Recognition of Prior Learning portfolio (e.g. which includes thorough review of previous education and relevant experience, as well as an academic skills assessment)
- Excellent communication and interpersonal skills
- A keen interest in working with children and adults with disabilities in local communities
- Some knowledge/experience of local disability and/or community development issues
- Computer literacy skills
- Persons with disabilities are actively encouraged to apply!

If you are interested in applying for the Higher Certificate in Disability Practice please send enquiries to: anthea.brinkman@uct.ac.za

Cost: R 32 540